THE PREVENTION OF FETAL SYNDROMES

IN BRITISH COLUMBIA

FINAL REPORT

May, 1991

for:

Communications and Education Branch
British Columbia Ministry of Health

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92-04594/

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1.0 INTRODUCTION

1.1 Background

Although Native health has traditionally been considered a federal responsibility, the Ministry of Health has recognized the need to respond to the changing national and provincial context of Native issues. The mission of the Ministry of Health, stated simply, is to maintain and improve the health of all British Columbians. In keeping with this, a number of initiatives have been developed in program areas across the Ministry which seek to improve the health of the Native population in this Province.

Although improvements in some health indicators among Native peoples have been demonstrated over the past 10 years, striking inequities remain. For example, neonatal mortality rates are 1.5 times the national average and mortality and suicide rates are 2.5 times higher than those of the general population (Native Health Working Group, 1990). The prevalence of preterm birth among Native people is double the rate among non-Natives. The rates of respiratory infection requiring hospitilization are considerably higher among Native children (Thomson & Philion, 1991). In addition, significant barriers to accessing health care services are experienced by Native people.

These concerns led to the establishment of a Native Health Working Group in 1989 within the Medical Services Commission under the direction of Dr. C.B. Henderson and is comprised of representatives from all Divisions of the Ministry. The mandate of the group is to "identify problems and to work in cooperation with the Native Community to ensure that health care needs are delivered effectively, efficiently and with culturally-appropriate sensitivity" (Native Health Working Group, 1990).

The Native Health Working Group initiated a series of consultations with Native organizations which identified the following major concerns:

- Native people are intimidated by and unfamiliar with the health care system;
- Native people are confused about health care coverage especially concerning responsibility for delivery of and payment for services; and
- Health education and promotion is unavailable, especially with respect to drug and alcohol abuse and Fetal Alcohol Syndrome (FAS).

The concern with the issue of FAS has been been previously identified as an important concern by other branches in the Ministry of Health. In 1988, the Ministry co-sponsored a conference in Vancouver concerning the prevention of alcohol related birth defects. The conference was organized by the British

Columbia Fetal Alcohol Syndrome Resource group (B.C. FAS Resource group), an advocacy group comprised of health care professionals from a variety of disciplines, each with a personal committment to the prevention of maternal drinking and the care of children with FAS/FAE.

During the conference, the provincial government announced a Pregnancy Outreach Project (POP) to be jointly funded by Alcohol and Drug Programs of the Ministry of Labour and Consumer Services and the Ministry of Health. Eight POP programs were subsequently implemented across the province. The aim of the Pregnancy Outreach Project is to assist women at risk for poor pregnancy outcomes by providing individual health counselling, group education, and peer support in terms of alcohol and drug abuse, smoking, diet and general prenatal health issues. The prevention of Fetal Alcohol Syndrome, Fetal Alcohol Effects and tobacco use are particular concerns (DeBeck, MacKinnon, von Hagen & McLean, 1990). Approximately half of the clients in the POPs are Native women.

While the initiatives described above represent an important first step in addressing the prevention of FAS, a much larger effort is needed to effectively solve the problem. Furthermore, it must be recognized that, although alcohol is the drug of choice among women in British Columbia (Native and non-Native), other substances are also being abused which have adverse fetal outcomes. This project will provide the background information necessary to determine the next step in the process.

It is important to state at the outset that we have concerns about the development of a Native specific Fetal Syndrome prevention program, in isolation from a broadly conceived, comprehensive strategy targeting the general population in British Columbia. While we recognize that it is essential to redress past and present inequities in health care for the Native population, care must be taken to avoid the implication that Fetal Syndromes (FS) are solely a Native health concern, which clearly they are not. A balance must be achieved between meeting the expressed needs of the Native community for culturally specific and appropriate prevention education on the one hand, and further perpetuating damaging stereotypes on the other. We believe that the recommendations presented in this report will satisfactorily address this concern.

1.2 Purpose

The purpose of this report is to:

a) provide an overview of the problem of Fetal Alcohol and other Fetal Syndromes in British Columbia with particular reference to the Native community;

b) review and assess existing Fetal Syndrome education programs and resources, particularly those developed for Native populations; and

c) present a series of recommendations for the development of a comprehensive Fetal Syndrome Prevention Program targeting the Native population in British Columbia.

The term Fetal Syndromes is used throughout this report to include the adverse fetal effects resulting from, in addition to alcohol, the use of cocaine, tobacco and other licit and illicit drugs and substances by the mother during pregnancy.

Although the purpose of this report is to provide an overview of the problem of Fetal Syndromes in British Columbia and to review existing prevention programs, there is an emphasis on alcohol use/abuse and FAS prevention. There are many reasons for this. In the first place, there has been very little work in the development and evaluation of prevention programs for fetal syndromes outside the context of FAS prevention. Secondly, alcohol is the drug of choice among childbearing women in Canada. It is a socially condoned and widely accepted drug and is often used in conjunction with other substances. The social acceptance of alcohol means that alcohol use during pregnancy may be more readily identified than other drug use. This may increase the likelihood of reaching women at risk for other other fetal syndromes.

Thus, the emphasis of this report on the prevention and treatment of alcohol use and FAS is partly pragmatic. However, the extensive research and program development in the area of alcohol and FAS prevention provides an excellent model for the development of prevention programs addressing other fetal syndromes. Many of the underlying principles and the theoretical basis are the same. It may, in fact, make the most sense to address the prevention of other fetal syndromes within the context of alcohol and FAS prevention.

This does, however, raise the issue of jurisdiction for alcohol and substance abuse prevention. In British Columbia, the mandate for alcohol and drug prevention programming belongs to Alcohol and Drug Programs of the Ministry of Labour and Consumer Services. Of all the fetal syndromes, only tobacco use falls within the mandate of the Ministry of Health. It could be argued, therefore, that a review of

this type is beyond the jurisdiction of the Ministry Health.

This is a difficult issue. The structural separation of Alcohol and Drug Programs from the Ministry of Health creates an artificial distinction between the prevention of alcohol/drug abuse during pregnancy and general perinatal health. Perinatal health clearly falls within the mandate of the Ministry of Health. However, a comprehensive prenatal and infant wellness program must address the issue of fetal syndromes prevention.

The close links between alcohol/substance use and other health issues (e.g. low birth weight) underscores the importance of integrating the prevention of alcohol and drug use during pregnancy into a comprehensive perinatal health program. This report may be useful in providing a context for the development of such a program.

2.0 STATEMENT OF THE PROBLEM

Over 81 percent of Canadians are alcohol users. Data from the recent Alcohol and Other Drug Survey (Health and Welfare Canada, 1990) indicate that the greatest proportion of current drinkers are in British Columbia (83%). The average British Columbian purchases 10.5 litres of absolute alcohol per year and consumes 3.8 drinks per week. Alcohol is clearly the drug of choice, although other drug use is also relatively common in British Columbia. This Province has the highest rates of exposure to crack/cocaine (2.1% of the population are current users) and marijuana (9.6%), and the second highest rate of opiate use (6.7%).

While alcohol and drug use in men is slightly higher than reported use among women, the highest rates of alcohol and other drug consumption in women occurs during the childbearing years (Health and Welfare Canada, 1990; Warren, 1985). This places a substantial proportion of women at risk for adverse fetal outcomes due to alcohol and drug use during pregnancy.

The problem with alcohol and drug use is obviously not restricted to any one racial group in the Province. However, the problem may be exacerbated in the Native community as a result of their demographic profile.

The Native population is younger than the general Canadian population with the majority of Native women aging into their childbearing years. This is in contrast to the remainder of Canadian women who are aging into their retirement years. Native women have higher fertility rates and are younger, on average, than other Canadian women. Fifty-five percent of Native mothers are under 25 years versus 28 percent of non-Native mothers. In addition, over 50 percent of Native women smoke during pregnancy as compared to less than one third of other women (Bobet & McBride, 1990).

When these factors are considered in light of the reported rates of alcohol abuse in Native communities (35 to 45 percent, Health and Welfare Canada, 1990), there is clearly concern that a large number of women are consuming alcohol during pregnancy.

The fetal effects of alcohol, tobacco and other drugs are potentially very serious. Fetal alcohol syndrome is estimated to be the **number one cause of mental retardation** in the western world (Streissguth & LaDue, 1987; Iber, 1980). Infants exposed to drugs in utero may be born addicted and suffer from a wide variety of adverse consequences.

These problems are not resolved with aggressive intervention; **damage is permanent** and children with FAS/FAE and other fetal syndromes may experience lifelong health problems. Most FAS children and many with other fetal syndromes will never be self-sufficient, either financially or socially, nor are they likely to be responsible parents themselves. They are at high risk for neglect, physical abuse, sexual abuse, violence, maternal death, and abandonment. Furthermore, children with FAS and other serious fetal syndromes are more likely to be in foster care, require special education, drop out of school, abuse alcohol and drugs themselves as adolescents and adults, and end up in the criminal justice system (Streissguth, LaDue & Randels, 1988; Segal, 1990).

Not only are fetal syndromes common, but they are also very expensive. Conservative estimates indicate that the lifetime care costs for the children born with fetal syndromes in 1991 in British Columbia are close to half a billion dollars. The present annual cost will be maintained or will increase of the trend in FS rates is not reversed.

FAS is now estimated to occur more frequently than the other two major causes of mental disability in children: Down's syndrome and spina bifida (Loock, 1990). In contrast to these two birth defects, however, **FAS is completely preventable**. All that is required is that a woman abstain from using alcohol during pregnacy. The issue is not quite that simple; pregnancy, however, appears to be a unique "window of opportunity" in that most women are highly motivated to do what is best for their babies. In fact, many women who drank heavily, smoked cigarettes, and/or abused drugs have been able, with appropriate help, to quit during pregnancy (Weiner & Larson, 1987; Weiner, Morse & Garrido, 1989; Segal, 1990).

Results from the evaluation of the British Columbia Pregnancy Outreach Project (DeBeck, MacKinnon, von Hagen & McLean, 1990) have demonstrated a marked reduction in alcohol use and smoking among women enrolled in the program. These results, while promising, must be interpreted with caution. The changes in behaviour which occured cannot be attributed with certainty to the effects of the program without an appropriate comparison group. However, these results do

point out that promising changes in alcohol and tobacco use do occur in many women during pregnancy. Thus, we must continue to develop and support strategies that capitilize on this "teachable" moment.

In view of the economic, emotional and social costs associated with FAS and other fetal syndromes, it is in our best interests to attempt to prevent these from occurring.

3.0 LITERATURE REVIEW - FETAL SYNDROMES

3.1 Fetal Alcohol Syndrome

Fetal Alcohol Syndrome (FAS) is a pattern of birth defects found in infants who were exposed to alcohol during pregnancy. FAS is the most serious result of fetal alcohol exposure and is characterized by structural facial abnormalities, nervous system dysfunction, hearing and speech disorders, joint and limb problems, small head circumference, heart abnormalities, low birth weight, post natal growth retardation, and mental retardation (Russel & Skinner, 1988; Church & Gerkin, 1988; Streissguth, 1986). When a child has some, but not all, of the characteristics necessary to make a clinical diagnosis of FAS, the child is said to be suffering from Fetal Alcohol Effects (FAE).

While it is not absolutely clear how much alcohol consumption is required to produce FAS and other fetal alcohol effects, there does appear to be a direct dose-response relationhip (Weiner & Rosett, 1984). In other words, the more heavily a woman drinks, the greater the probability of having an affected child.

On the other hand, no safe level of consumption has been established. With any given individual, the amount of alcohol consumption required to produce effects may be related to other factors such as genetic makeup, nutritional status, smoking, and the use of other drugs (Plaiser, 1989).

3.1.1 Incidence and Prevalence of FAS/FAE

The worldwide incidence of FAS has been estimated at 1.7 per 1000 live births with the rate increasing to 3.3 per 1000 as older children are later identified (Abel & Sokol, 1987). In a study of three southwestern Native American tribes in the United States the reported incidence rates varied from 1 per 100 to 1 per 750 live births (May, Hymbaugh, Aase & Samet, 1983). Sokol (1988) suggests that the incidence of Fetal Alcohol Effects may be 5 to 10 times higher than the rate of FAS.

The incidence of FAS in Alaska is estimated at 4.4 per 1000 live births and the rate of FAE is estimated at the low end to be 2 times the FAS rate and at the high

end to be 15 times the FAS rate (Munson, Lally & Felix, 1990). FAS has been identified in virtually every country where alcohol is used.

High rates of FAS/FAE have been reported in British Columbia and the Yukon where, in some communities, the prevalence was found to be as high as 1 in 5 (Robinson, Conry & Conry, 1983). In 1985, Dr. Kwadwo Asante conducted a survey to determine the frequency of FAS/FAE among the handicapped population of children in 23 northern British Columbia communities and 15 in the Yukon Territory (Asante & Nelms-Matzke, 1985). The prevalence of FAS/FAE was one handicapped child in three.

While there have been criticisms of these studies on methodological grounds (Bray & Anderson, 1989), the evidence is strongly suggestive that FAS is indeed a problem in British Columbia. The B.C. FAS Resource Group states that an incidence rate of 3 to 4 per 1000 live births may not an unreasonable estimate for the British Columbia population.

In 1990/91, over 42,000 babies will be born in British Columbia. Using the estimate of 3.3 per 1000 live births, we can estimate that approximately 136 infants will be born with FAS in British Columbia this year. If the rate of FAE is 5 times the FAS rate, then an estimated 680 infants will have FAE and other alcohol related birth defects.

The incidence and prevalence rates of FAS are reported to be higher among the Native than the non-Native population in B.C. (Asante, 1990). This is not surprising given that the estimated rates of alcohol abuse among the Native population in Canada range from 35 to 45 percent (Health and Welfare Canada, 1990). Recent submissions by Native bands, Tribal Councils and Native agencies to the British Columbia Royal Commission on Health Care and Costs, clearly identify alcohol and substance abuse as a primary concern in Native communities across the Province.

There may, however, be other factors contributing to an apparently high rate of FAS in the Native community. There is evidence that other maternal "environmental" factors such as nutritional status and tobacco use may contribute to a poorer pregnancy outcome in alcohol and drug abusing women (Schneider, 1986; Plaiser, 1989). The overall inequities in Native health in this province may be a contributing factor to the apparently high rate of FAS among Native people.

Munson, Lally & Felix (1990) also suggest that it is not clear whether Native people do, in fact, have greater difficulty with alcohol or if the perception of alcohol as a Native problem has caused them to be identified at a greater level than their representation in the population. Physicians are either unable or reluctant to identify FAS (Brynelson, 1990). It may be that the identification of alcoholism as

a Native problem results in a greater likelihood of a Native child being diagnosed as FAS.

It is impossible to consider the issue of FS and alcohol/substance abuse outside of their societal context. There is evidence that the patterns of alcohol and substance use/abuse among Native peoples spring primarily from the inequities faced by them in Canadian society. This is supported by recent results from the National Alcohol and Other Drugs Survey (Health and Welfare Canada, 1990) which indicate that alcohol abuse in the Native population is more likely to occur among individuals with lower income, education and occupational status. The opposite is true in the general population.

3.1.2 Financial Burden

Infants born with Fetal Alcohol Syndrome impose a substantial financial burden on the health care, education, social service and criminal justice systems. The cost of hospital care for a low birth weight infant has been estimated at $500 to $1000 per hospital day (DeBeck, MacKinnon, von Hagen & McLean, 1990). Many infants born with FAS require a stay in the neonatal intensive care unit. Estimates of the cost for a twenty-four hour stay in the intensive care unit range as high as $40-50,000 (Growe, 1990). The cost of caring for an FAS child for his or her lifetime (including special education costs) has been conservatively estimated at $1 million (Hild, 1988; Streissguth & LaDue, 1987; DeBeck, MacKinnon, von Hagen & McLean, 1990). It is not clear whether this takes into account the cost of FAS to social services or the criminal justice system. This cost is extremely difficult to quantify but could be significant.

As stated above, an estimated 136 FAS children will be born in B.C. this year. Using the conservative estimate of $1 million per child, $136 million will be required to care for these children throughout life. The costs of caring for FAE children may well be as expensive as caring for FAS children depending on their level of disability. However, even if the average costs for FAE children are only half that of caring for FAS children, $272 million will be required to care for the estimated 680 FAE children to be born this year. If the birth rate in British Columbia remains the same next year and we do nothing to prevent the occurance of FAS, another 136 children may be born with FAS and 680 with FAE thus costing an additional $408 million over their lifetimes. This will continue for every year that FAS rates remain high.

These estimates are, of course, highly speculative. It is clear, however, that there is an enormous price tag associated with a completely preventable condition.

Taking a somewhat more conservative appoach, we can base our calculations on actual numbers. In 1989/90, 13 children diagnosed with FAS were referred to the Infant Development Program of B.C. (IDP). An additional 18 children with suspected FAS/FAE were referred. Thus, $31 million will be required to maintain these children throughout life. However, a recent report to the Royal Commission on Health Care and Costs suggests that there is a significant under-reporting of FAS in B.C. (Brynelsen, 1990).

3.2 Other Fetal Syndromes

Use of other drugs can also result in adverse effects on the fetus. In fact, adverse fetal effects have been demonstrated with use of a wide variety of different drugs, both licit and illicit.

3.2.1 Cigarette Smoking

A dose-response relationship has been demonstrated between the number of cigarettes smoked during pregnancy and the risk of cancer in the child (Stjernfeldt, Berglund, Lindsten & Ludvigsson, 1986).

Exposure to cigarette smoking by the mother results in low birthweight and preterm birth (Rubin, Krasilnikoff, Leventhal, Weile & Berget, 1986; Stjernfeldt, Berglund, Lindsten & Ludvigsson, 1986; Shiono, Klebanoff & Rhoades, 1986; Stewart & Dunkley, 1985; Feldman, 1985), increased neonatal morbidity and mortality, and long term effects on general health, scholastic achievement, and behaviour (Feldman, 1985). The incidence of Sudden Infant Death Syndrome (SIDS) among infants exposed to smoking in utero is 2.5 times the rate in the general population (Feldman, 1985).

Prenatal exposure to cigarette smoke has also been associated with poorer language development and lower cognitive scores at 36 and 48 months after birth (Fried & Watkinson, 1990). Even passive exposure of the fetus to smoking by the father may result in low birthweight (Rubin et al, 1986).

Intervention studies have demonstrated that smoking can successfully be reduced or eliminated by women during pregnancy. In fact, many women spontaneously quit upon learning of pregnancy. Women who continue to smoke after the third month of pregnancy tend to have less than a Grade 11 education, are more likely to be living common law, or to be teenagers (Stewart & Dunkley, 1985). **The risk of low birthweight can be dramatically reduced if quitting occurs early in pregnancy.**

The costs associated with exposure to cigarette smoking in utero are very difficult to quantify. However, the intensive care costs of infants with smoking related low

birth weight parallels the data reported in the previous section on the financial burden of FAS.

It has been suggested that the consequences of cigarette smoking during pregnacy are severe enough to justify coining the term "Fetal Tobacco Syndrome" (Neiberg, Marks, McLaren & Remington, 1985).

3.2.2 Marijuana

Marijuana use during pregnancy has been associated with decreased length of gestation and lower birthweights (Fried, 1980; Fried, Watkinson & Willan, 1984; Hingson et al, 1982). At 48 months after birth, lower scores in verbal and memory domains have also been demonstrated (Fried & Watkinson, 1990).

3.2.3 Caffeine

Caffeine use has been weakly associated with a variety of poor pregnancy outcomes, including low birthweight, and an increased risk of prematurity (Schneider, 1986).

3.2.4 Cocaine Use

The incidence of cocaine use in the United States has risen among adolescents (Schneider, 1986) and women between the ages of 18 and 34 (Keith, MacGregor & Sciarra, 1989). The incidence in Canada is also increasing (Health and Welfare Canada, 1990) particularly in larger urban areas. Many cocaine addicted babies are being seen in Sunnyhill Hospital in Vancouver.

The use of cocaine during pregnancy increases the risk of preterm labour, low birth weight, and small for gestational age babies (McGregor, Keith, Chasnoff, Rosner, Chisum, Shaw & Minogue, 1987). There is also an increased risk for perinatal death due to placental abruption, and major malformations (Bingol, Fuchs, Diaz, Stone, & Gromish, 1987).

Women addicted to cocaine generally have many problems associated with their addiction that complicate the pregnancy such as: legal entanglements, poor medical compliance, poor nutritiion, poor general health, and polydrug use (Keith, MacGregor & Sciarra, 1989). Babies born to these women may also be addicted to the drug.

3.2.5 Heroin and Methodone

There are 1300 people in Canada on Methadone maintenance, of which 1100 are in British Columbia (personal communication, Rick Hudson, Ministry of Health,

February 27, 1991). A large proportion of these are women of childbearing age. Heroin addiction also represents a significant proportion of those addicted to narcotics. Often women on heroin or methadone have amenhorrhea secondary to drug use and thus become pregnant without knowing it. Thus, drug use continues through the critical early months of pregnancy resulting in serious consequences for the fetus.

Women addicted to heroin, methodone and cocaine (and other drugs) give birth to babies that suffer a variety of serious effects: neonatal asphyxia, intercranial hemorrhage, interuterine growth retardation, low birthweight, and long term developmental delays. They are born addicted and therefore suffer from Neonatal Abstinence Syndrome (NAS). Extreme irritability, excessive crying that is inconsolable, tremors, hypertonicity, hyperactivity, disorganized sleep patterns, sweating, nausea, vomiting, and seizures are common symptoms in these infants (Keith, MacGregor, and Sciarra, 1989; Segal, 1990).

These babies are very difficult to care for and often remain in the neonatal intensive care unit after birth and throughout the withdrawal period (at signficant cost to the health care system). Often the children are apprehended by the Ministry of Social Services and Housing, placing strain on the foster parenting program. Long term developmental delays and behaviour problems are common. Last year, 52 NAS children were registered in the Province's Infant Development Program (Brynelson, 1990). The developmental and behaviour problems experienced by these children puts them at risk for abuse and neglect. They are also at significantly higher risk for Sudden Infant Death Syndrome (Segal, 1990).

Sunnyhill Hospital in Vancouver is the location of an internationally renowned NAS clinic. It is the only one of its kind in Canada and is run by Dr. Sidney Segal, a pediatrician who has devoted his life to the care and treatment of these infants and their mothers. Over 80 babies with NAS (many of them Native) were treated in the clinic last year. Many of the women in the program have successfully stopped using drugs under his care.

Prevention should clearly be a priority in dealing with the problems associated with drug use. It is estimated that up to 60 percent of pregnant addicts in the United States receive no prenatal care (Schneider, 1986). While the figure may not be as high in Canada because of universal medical care, the figures are still likely to be high.

Providing care to addicted women is considerably more costly. It is inherently more difficult because of the problems in identifying them and keeping them in treatment. It requires more skilled personnel, and the infants born to such women require more intensive treatment. The estimates of lifetime care for a developmentally handicapped NAS child may be similar to the cost of caring for

an FAS child. Often these infants have low birthweight, are premature and suffer from major malformations. Even without major malformations, developmental delays and behaviour problems are common.

4.0 PREVENTION OF FETAL SYNDROMES

4.1 What is Prevention?

Prevention is defined as "a constructive process designed to promote personal, social, economic and political growth of the individual, family and community toward their full human potential and, accordingly, to inhibit or eliminate alcohol and other drug induced conditions that cause impairment of health and personal, social and economic prosperity" (Munson, Lally & Felix, 1990). This definition of prevention implies a complex, multidimensional process which clearly represents a major public health challenge.

Strategies for prevention have typically been categorized as being either primary, secondary or tertiary. These distinctions tend to be somewhat arbitrary and may involve significant overlap in terms of the focus of activity.

4.1.1 Primary Prevention

Primary prevention is the actual prevention of disease. It precedes disease and prevents it from developing. Primary prevention at the population level has typically consisted of health education, communication and promotion efforts aimed primarily at increasing individual and public awareness of causes and consequences. An underlying assumption is that awareness of a consequence will prevent or change the behaviour causing the consequence and therefore the disease or dysfunction will be arrested before it develops. At the individual level, primary prevention programs may focus specifically on preventing or changing risk behaviour before the undesirable outcome occurs.

In the case of FS, primary prevention by this definition would consist of educating women who are not pregnant but in their childbearing years, or are pregnant but at low to moderate risk for drinking, smoking or using drugs during pregnancy (Ronan, 1985). Primary prevention would also consist of ensuring support networks are in place and educating community members such as bartenders, educators, and the public at large to make the pregnant woman's environment nonconducive to alcohol consumption, tobacco and other drug use. School based prevention programs would also be included here. Primary prevention is viewed by most health professionals as the optimal type of prevention, and potentially the most cost effective.

4.1.2 Secondary Prevention

Secondary prevention consists of the identification of high risk groups in the interest of arresting the further development and disability of disease. In the case of fetal syndromes, secondary prevention involves the identification of women who drink, smoke or use drugs while pregnant, women who are chronic alcohol and substance abusers, or women who have had one fetal syndrome child. It consists of interventions to reduce or eliminate drinking, smoking and/or drug use among women in these high risk groups in the hope of preventing or arresting damage to the fetus. Secondary prevention has also been referred to as "early intervention".

4.1.2 Tertiary Prevention

Tertiary prevention is the limitation of disease or management of disease to enable the person to live life to its full potential within the constraints of the disease. In the case of the fetal syndromes child, it may mean referring the child to appropriate treatment or counselling facilities. This may include special education, speech therapy, hearing aids, or any other type of support that would enable the child to reach her or his full potential.

Tertiary prevention may also mean referring the mother of an affected child to an appropriate treatment facility. Referral at this stage may include respite care or counselling and therapy. This may decrease her risk of having another fetal syndrome child, in which case it could arguably be called primary prevention.

4.2 Which is Best - Primary, Secondary or Tertiary?

There is increasing emphasis in the literature on the importance of primary prevention. A worldwide movement toward primary health care and the importance of primary prevention are reflected in key Canadian policy documents (Epp, 1986). Concern about the high cost of acute and chronic health care delivery has given primary prevention a high profile. As stated above, primary prevention is viewed as the optimal and most cost effective type of prevention.

Recent developments in the prevention field emphasize community development as an important primary prevention strategy. Witness the groundswell of support for the "Healthy Communities" concept in this country and around the world. Models of effective community development approaches to the problems of alcohol and substance abuse have only recently come to the attention of mainstream prevention researchers and program developers. For example, phenomenal success has been achieved in reducing the rate of alcohol abuse in a small Native community in the interior of British Columbia. Over a 20 year period, the Alkali Lake Indian band has reduced the rate of alcohol abuse among the adult population from 100 percent alcoholism to 95 percent sobriety.

Other examples of successful primary prevention interventions include campaigns to reduce drinking and driving. The marked reductions in smoking over the past few decades have also been attributed to widespread primary prevention efforts.

The important point to note is the long term nature of these interventions. The results are not immediately apparent. In fact, it may take two to three generations for the ultimate benefit of many primary prevention approaches to be realized. There is little argument among prevention experts and practitioners that community-based, community-driven approaches represent the best bet for long term prevention success.

In the meantime, however, some women continue to drink, smoke and use drugs during pregnancy thus placing themselves and their infants at immediate risk for adverse pregnancy outcomes. While clearly essential in the overall strategy to improve the health of the population, primary prevention, by its very definition, does not target or reach at-risk groups. This is the major weakness in recent efforts to prevent fetal syndromes. The example of FAS illustrates this point.

The rate of FAS among the general population worldwide has been estimated at approximately 2 per 1000 live births, with marked regional variations. However, most FAS babies are born to women who are chronic alcohol abusers. It has been estimated that 50 to 70 percent of women who abuse alcohol will have a baby affected by FAS/FAE. The incidence of FAS rises to 29 per 1000 live births among women who are chronic drinkers (Warren, 1985).

Thus, short term prevention efforts which target the at-risk population are essential to any comprehensive approach. Secondary and tertiary prevention must be integrated into the overall prevention strategy. In British Columbia, secondary and tertiary efforts are minimal. Secondary and tertiary efforts may, in fact, enhance the primary prevention efforts. Results of studies in the smoking prevention field confirm that school based primary prevention programs are more successful in communities with on-going, secondary prevention efforts (Perry, Murray, Leupker & Hearn, 1990).

Furthermore, there is considerably more evidence for the success of secondary prevention efforts in preventing fetal syndromes than there is for primary prevention approaches. It has been demonstrated that programs aimed at reducing or eliminating drinking, smoking and substance abuse among chronic pregnant users have been extremely successful.

In contrast, hard evaluation data documenting the effectiveness of primary prevention efforts are not generally available. It is very difficult to measure the effectiveness of a primary prevention program when the outcome of interest (i.e.

an affected infant) will not exist to measure if the program has been successful. Demonstration of a pre to post intervention reduction in the prevalence of a Fetal Syndrome in a community would be a reasonable indication of success. This is generally impossible, however, due to the fact that accurate pre intervention measures of incidence and prevalence are not usually available.

There is also evidence that political and structural interventions which do not technically fit the definitions of primary, secondary or tertiary prevention may be very successful in prevention efforts. For example, high taxes have successfully reduced cigarette sales. Raising the drinking age has reduced the number of alcohol related traffic fatalities in the United States. Health warning labels for tobacco and saccharin have been demonstrated to affect consumer behaviour (Smart, 1990; Richardson, Reinhart, Rosenthal, Hayes & Silva, 1987). Very inexpensive interventions such as raising the drinking age, putting warning labels on alcohol products, alcohol price increases and restrictions of tobacco sales to minors may have more dramatic and immediate effects on the prevention of fetal syndromes than other more costly approaches.

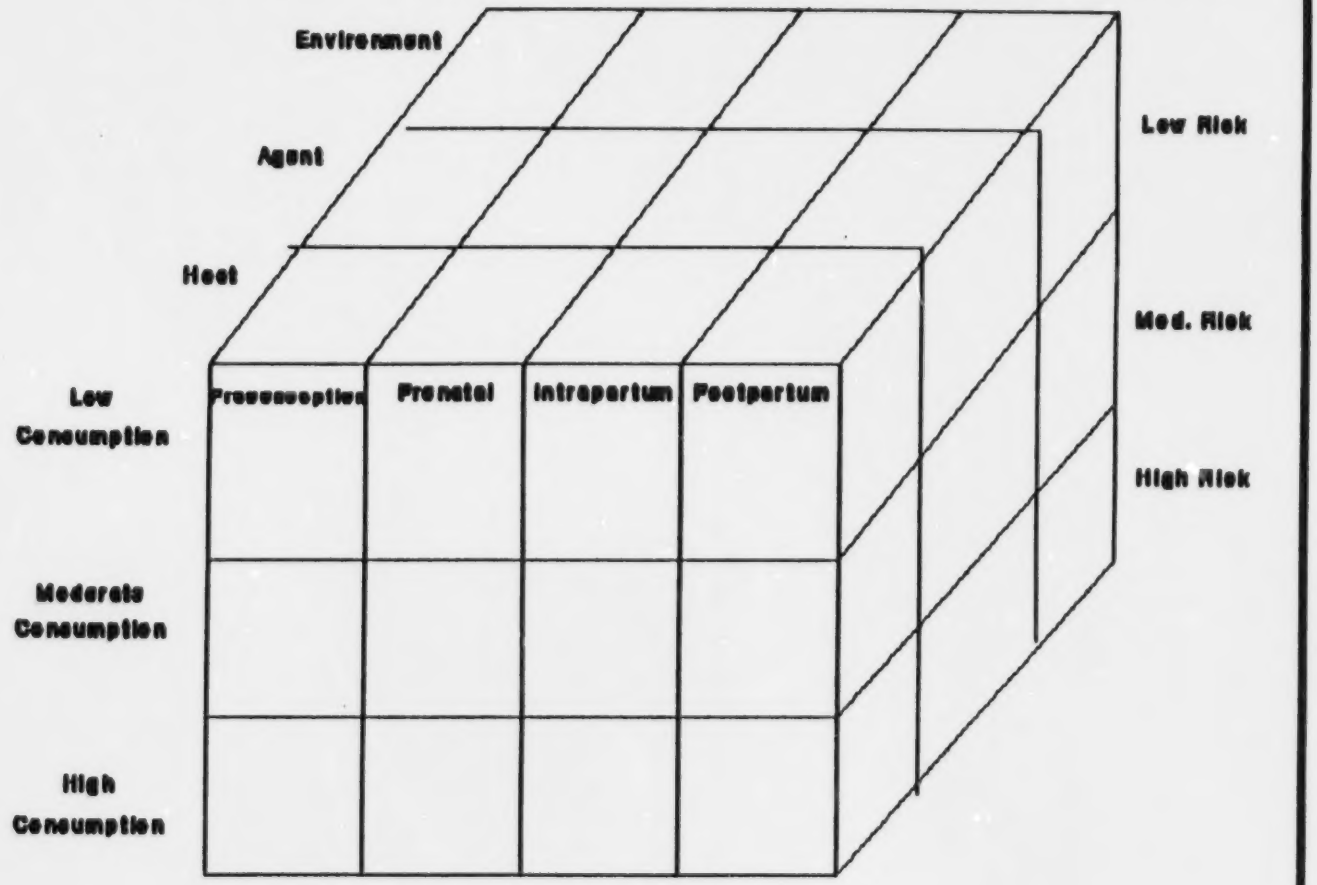
Clearly, prevention of alcohol and substance abuse in general, and fetal syndromes in particular, will require an intensive, integrated and comprehensive strategy. The societal origins of alcohol and substance abuse imply the need for macro level interventions (Schinke, Gilchrist, Schilling, Walker, Locklear, Bobo et al, 1986). The following model is suggested as an appropriate planning framework for the development of a comprehensive strategy for the prevention of fetal syndromes in British Columbia.

4.3 An Alternate Model of Prevention

The complexity of the determinants of substance abuse and thus the demand for multiple levels of prevention require a more sophisticated and heuristic model for planning and describing prevention activities, rather than discussing them simply in terms of primary, secondary and tertiary prevention. Furthermore, the focus of prevention strategies categorized as primary, secondary and tertiary have tended to be "top down" types of approaches. Newer conceptualizations of prevention activities include community based, organized and directed processes that are "bottom up" approaches. A useful model will incorporate both types of approaches.

In order to avoid the conceptual overlaps inherent in the above definitions of prevention and to expand upon them, we have adapted a model that provides, in our view, a more useful framework for discussing specific strategies for the prevention of alcohol and substance abuse and its consequent fetal effects (refer to Figure 1). The three dimensional format has been used to conceptualize the dimensions of health behaviour interventions (Best, Brown, Cameron, Smith and

FIGURE 1: FAS Prevention Planning Model



MacDonald, 1989) and as a health planning model (Shannon, 1990). In fact, the model presented here could form the basis of a useful prevention planning tool.

The first dimension is derived from the "continuum of risk" model, an alternative framework for substance abuse prevention developed by the Ontario Ministry of Health in conjunction with the Addiction Research Foundation, Toronto. This model is based on the amount of alcohol or drugs an individual consumes, and the belief that risk increases as consumption increases. A core belief is that individuals who have different consumption levels have different needs, ranging from health promotion to treatment and recovery (Ontario Ministry of Health, 1988).

Because our focus is on perinatal health and the prevention of fetal syndromes related to substance abuse we are incorporating a second dimension in this model which identifies the timing of the intervention along the maternal-child health care continuum, from preconception through prenatal and intrapartum to postnatal (Beardsley, Gillespie & Williams, 1985). The type of intervention will vary depending, not only upon the risk category of the individual woman, but also on her reproductive status.

The third dimension of the model relates to the focus of the prevention effort. For this dimension we have selected the epidemiological model, which identifies the host, agent or environment as the focus of intervention. The host refers to the person who uses alcohol or other drugs. The agent is the alcohol, tobacco or drug itself and the environment refers to the setting or context in which the drinking, smoking or drug use occurs (Munson, Lally & Felix, 1990).

Interventions targetting the host would involve strategies which seek to prevent or modify alcohol and substance use in the individual. Focusing on the agent would involve such strategies which limit the distribution and availablility of the substance in question, such as legislation restricting the drinking age, requiring warning labels on alcohol products and restricting tobacco sales.

Finally, interventions targeting the environment would focus on advertising, public education, changing social norms, and reducing social acceptance and support for use of the substance, especially during pregnancy. Efforts targeting individuals in the users support network would be included here. Appendix A provides a table of potential fetal syndromes prevention strategies that are organized along the dimensions outlined in the above model.

The importance of including a range of strategies at every level of prevention is clearly indicated. This notion is supported in the review of existing fetal syndromes prevention programs described below.

4.4 Effective Fetal Syndrome Prevention Programs

In order to determine the constituents of an effective fetal syndromes prevention program, several comprehensive community-based programs were reviewed. No programs were identified which focused specifically on prevention of substance or drug abuse during pregnancy outside the context of alcohol use. The reason appears to be that, although the use of other drugs during pregnancy does occur, the abuse of alcohol is far more common and most drug users also use other drugs, including alcohol. By focusing on alcohol, as a socially condoned and legal drug, the probability is higher of identifying and reaching more of the at risk population. Thus, the programs reviewed here are primarily Fetal Alcohol Syndrome Prevention Programs.

A great deal of what we know today about effective prevention comes from the widespread development, implementation and evaluation of successful community-based substance abuse prevention programs over several decades in the United States. Most of the programs reviewed here are American, primarily because no similar programs were located in Canada.

Appendix B provides a detailed description of several prevention programs in terms of the target group, program components, implementation, and evaluation (where data are available). Most of the programs described are illustrative examples of effective programs. Several have been cited as "Exemplary" prevention programs (National Association of State Alcohol and Drug Abuse Directors, 1989).

There appeared to be several key elements in these programs which influenced success. Most programs incorporated primary, secondary and tertiary prevention strategies. In programs where the major emphasis was on primary prevention, recommendations for a greater emphasis on secondary and tertiary prevention were made. Many programs focused on families and the community, in addition to the individual.

The most successful strategies were those which targeted at risk women and intervened early in pregnancy to help women quit drinking. Family and community support appeared to enhance efforts. The availability of referral networks and counselling services were important elements of success. A key element in most programs was the training of professionals and paraprofessionals in early intervention techniques, such as risk assessment, counselling and referral. Thus, a "train the trainer" approach was identified as being very successful.

Primary prevention efforts generally involved a wide range of strategies to increase public awareness of the risks of drinking during pregnancy and were successful in increasing the level of public and professional knowledge. Unfortunately, few programs actually measured changes in drinking behaviour among the general

public.

Two of the programs reviewed were implemented specifically in Native communities. The emphasis of the first program was on primary prevention and the major strategy involved a "train the trainer" approach in order to widely disseminate information about FAS and prevention of FAS. There was a significant impact on the level of knowledge and awareness of the population. Knowledge was the major outcome variable. A number of recommendations for improvement were made which included:

1. The need for built-in mechanisms to encourage the continuation of prevention efforts beyond the demonstration period.
2. The need for baseline screening for FAS which would serve to increase the motivation of staff by providing data for better evaluating success, and would also enable a stronger focus on secondary and tertiary efforts.
3. Secondary and tertiary prevention need to be more highly emphasized.
4. There should be more emphasis on reaching high risk groups.
5. Standards for referral should be developed which would ensure more consistent and effective follow up.

The second program, which was implemented in Tuba City, Arizona had an impressive success rate. Approximately 66 percent of women who entered treatment before the third month of pregnancy quit drinking. There was a strong focus on families and the community as well as the individual. Both programs utilized culturally appropriate resource material developed specifically for use in the target communities.

Most of the programs reviewed generally met the "criteria for effective programs in alcohol and substance abuse prevention" developed by the National Association of State Alcohol and Drug Abuse Directors, the National Prevention Network, and the Office for Substance Abuse Prevention in the United States.

These criteria are summarized below, while a detailed description of the criteria is included in Appendix C.

In general, effective prevention programs for alcohol and substance abuse prevention have the following attributes:

1. The progam is based on a sound planning process which reflects involvement of a broad range of community systems.
2. There are specific, measurable goals and objectives.
3. The program utilizes multiple activities, implemented in sufficient quantity to achieve the objectives.
4. There are multiple target groups at all risk levels.

5. There is a strong evaluation base.
6. The program takes into account the unique and special needs of the community (i.e. culturally sensitive and appropriate).
7. The program is an integrated, essential component of the health care system.
8. There is widespread community involvement and the community takes ownership of the problem.
9. The program reflects a long-term strategy.
10. The program utilizes multiple social systems and levels in the community in a collaborative effort.
11. A marketing strategy is used to showcase the positive effects in the community, which may be directed at policy makers.
12. The program is documented in sufficient detail so as to be replicable.

These attributes also advance the "principles of successful community-based programs" developed by Shannon (1990) and based upon his tobacco, cocaine, and cardiovascular intervention programs implemented in the City of Toronto.

We recommend that these criteria be used in the British Columbia prevention planning process because they reflect state-of-the-art research, knowledge, and experience.

4.5 Informal Key Informant Survey

Most of the FAS prevention programs reviewed were developed and implemented several years ago. In order to obtain up to date information on current prevention activities and perspectives, an informal, unstructured telephone survey of key informants was conducted. The key informant group was comprised of individuals with very diverse backgrounds and perspectives. Most are involved in alcohol use prevention and are primarily concerned with FAS versus other fetal syndromes. For example, the group included members of the B.C. FAS Resource Group, FAS researchers and clinicians in the United States and Canada. Also included were Native people in B.C. with interest and expertise in general Native health issues, and program coordinators of successful FAS prevention programs (Native and non-Native). The purpose of the survey was to identify:

a) additional resource people working in the area of FAS prevention
b) the issues related to FAS prevention at the community level;
c) the prevention strategies and materials currently being utilized;
d) FAS prevention programs that specifically target the Native population;
e) perceptions of what types of programs, materials, and resources are needed to address the issue of FAS prevention.

The list of key informants was generated by reviewing the current literature to

identify those conducting FAS prevention research and by contacting members of the B.C. FAS Resource Group. Each person contacted was asked to identify others who were doing innovative work in the field.

The materials and programs identified in this survey are included in the program review described in Section 4.4, and the materials review described in Section 5.4.1.

The purpose of the survey was not to conduct a methodologically rigorous study, but rather to "educate" the reviewers and provide them with a general "feel" for and understanding of the salient issues. The interviews took the form of an informal conversation about FAS in particular and prevention issues in general.

The comments made by each informant were recorded. The data were then reviewed and general themes were extracted. Comments were then categorized according to those themes. The major themes are outlined below with several illustrative comments which reflect that particular theme:

1. Effective Prevention is Community Based

    - community development approaches will be the most effective in the long term
    - the community must identify the problem and assume responsibility for dealing with it
    - the community must determine the strategies to use and obtain broad based support for implementation

2. To Be Effective, All Levels of Prevention Must Be Addressed

    - primary prevention targets low risk individuals and will not be effective in reducing incidence in the short term, but will be most effective in the long term
    - secondary and tertiary prevention efforts focusing on woman at risk are critical

3. Effective Prevention is Multi-Faceted

    - a broad range of social systems within the community must be involved (e.g. school, church, local government)
    - needs to involve many grass roots groups, community health agencies, health and social care providers, individuals and families

4. Effective Prevention in Native Communities is Based on Cultural Values and Traditions

   - must incorporate Native interpretations and Native healing methods
   - Native cultural values can provide a useful framework for prevention
   - materials must be culturally appropriate
   - must rely less on written materials and more on oral communication, using models and stories Native people can relate to in the context of their own lives

5. Government Should Play a Supportive vs Directive Role

   - must focus on eliminating the gaps and overlaps in service
   - must communicate, coordinate and collaborate within and between levels of Government
   - provide funding and support services but relinquish control and direction to the community.

6. Training of Health Care Workers is Essential

   - a train the trainer approach has been demonstrated to be an effective means of rapidly diffusing information
   - physicians and community health workers need training on the identification of at-risk women, and FAS infants.

7. FAS Cannot be Seen Outside of Its Broader Social Context

   - FAS must be seen as part of a larger social issue
   - the focus should be on reducing or eliminating alcohol use in general

Essentially, these themes can be viewed, in a broad sense, as expert recommendations for effective FAS prevention programming. It is interesting that the general recommendations identified by the key informants parallel, at least to some extent, the criteria for effective prevention programs outlined in Sections 4.4 above.

5.0 PREVENTING FETAL SYNDROMES IN THE NATIVE COMMUNITY

5.1 Native Specific versus General Population Approach

There is some debate within the Native community itself about whether or not there should be a Native specific fetal syndromes prevention program in this province. General discussions with members of the Native community by the reviewers has revealed two distinct positions on the issue.

On the one hand, concern has been expressed that targeting the Native population for FS prevention labels the problem as a "Native" issue. This may serve to reinforce negative stereotypes of Native people. Focusing on FS as a Native issue may also detract from the pressing need to deal with the more fundamental issues like aboriginal rights and title, land claims, structural and systematic oppression, discrimination and poverty. If the government chooses to invest money in a "Native" problem, this may only serve to diffuse the larger and more critical issues.

On the other hand, FS babies continue to be born in the Province, many of them Native. FAS has been identified as a problem by the Native community; the community has taken ownership of the problem and wishes to address the issue. Native health issues and needs differ from those of the mainstream population. Many members of the Native community believe that resources, programs and materials which are culturally appropriate and targeted specifically to local needs must be developed. The concern is that if a general population approach is used, there is a danger that the needs of the Native community for fetal syndromes prevention may not be met.

We must be certain to address both of these important concerns in any initiatives undertaken by the Province.

5.2 What Prevention Strategies Work in Native Communities?

Although there has been some discussion of prevention programs in Native communities, the focus of the discussion thus far has been on general fetal syndromes prevention. What do we know specifically about prevention in Native communities? Are the prevention strategies which are used successfully in the general population equally effective in Native communities?

Presently, there are few data which allow us to answer these questions definitively. We do not know whether the successful prevention strategies developed elsewhere are universally generalizable to the Native population, particularly in British Columbia. Vast cultural differences exist between the various Native tribal groups in this province. The coastal aboriginal people have a fundamentally different way of life than do the Plains Indians in the United States, which are the groups for which most Native specific prevention programs have been developed.

The data that are available, however, do provide us with some clues as to the direction we should be moving. Two of the programs reviewed in Section 4.4 above were developed specifically for use in Native communities. The strategies used were essentially the same as those used in other successful programs. The only difference with these programs was the use of local Native staff and trainers, and the development of culturally specific and sensitive education materials and processes.

The recent paradigm shift in health promotion which emphazises the importance of community development strategies may be particularly relevant to prevention in Native communities. In Native culture, *community* rather than *individualism* forms the normative base (Pedigo, 1983). Although there are vast cultural differences among different tribal groups, most Native cultures are based on a value system in which there is a "community consciousness" and community survival is a predominant theme.

The unprecedented success of the Alkali Lake band in reducing the rates of alcohol use in their community may be related to this underlying value. It may be that a cultural system in which the individual is viewed as an extension of the community provides the appropriate context for successful community development. Recent conceptualizations of health promotion processes specify the importance of identifying community competencies. It may be that Native communities have unique strengths which support and enhance community development approaches. Clearly more research is needed to answer these important questions, but it may be that we will not see the same level of success with similar approaches in non-Native Canadian communities.

The Alkali Lake example provides some instructive insights. The strategies utilized there included self-help and mutual aid programs, economic incentives, community sanctions, and education. In fact, most of the strategies fit nicely into the "Achieving Health for All" framework (Epp, 1986), which emphasizes self-care, mutual aid and healthy environments as the health promotion mechanisms. The implementation strategies in the framework involve fostering public participation, strengthening community health services, and coordinating healthy pubic policy. All of these health promotion mechanisms and strategies were used to some degree in the Alkali Lake community.

It would appear that prevention strategies which have been used successfully in non-Native communities may be equally (or even more) relevant for use in Native communities provided they are culturally sensitive and are based on Native cultural traditions. It is not immediately clear how the concept of "cultural sensitivity" can be operationalized. This will obviously need to be done by each community.

An interesting model of this "operationalization" is a collaborative project between the Meadow Lake Tribal Council in Saskatchewan and the University of Victoria (UVIC) School of Child and Youth Care. UVIC has been contracted by the Meadow Lake Council to develop a training program for day care providers under a grant by the federal Child Care Initiatives Fund.

The need for cultural appropriateness was a major criterion in the curriculum development. To achieve this, the curriculum developers involved community members and elders in a "reinterpretation" of western theories of child

development (e.g. Piaget) in the context of Native experience. The curriculum was then written from this perspective. In addition, the curriculum was adapted to the varied literacy levels of the students (personal communication, Vicki Mulligan, UVIC, March, 1991). A similar model could be used for the development of culturally appropriate fetal syndromes programs in British Columbia.

5.3 Native Health Care Worker Survey

In order to make recommendations for FS prevention in the Native population, it was first necessary to determine the current status of community prevention activity as well as perceptions of the needs with respect to prevention. A survey of health care workers providing direct services to Native clients was conducted. The purpose of the survey was to identify FS prevention education needs, issues and appropriate strategies. The emphasis, once again, was on FAS versus FS, primarily because the concept of FAS is readily understood by the participants. Much of the information obtained, however, was relevant for understanding the issues of FS prevention in these communities.

Three groups of individuals who were considered most likely to be in contact with at-risk clients, or who had a mandate to conduct drug and alcohol counselling or education with Native clients were interviewed by telephone: Pregnancy Outreach Project Coordinators (N=8), Friendship Centre Drug and Alcohol Counsellors (N=15), and Community Health Representatives on reserves (N=31). Refer to Appendix D for a detailed description of the methods and findings.

5.3.1 Results

The majority of survey participants felt that FAS was a priority concern in their communities. Two thirds of the respondents (66 percent) did believe that FAS was priority concern. However, only half of the CHRs believed FAS to be a problem in their communities. Of those who did not think it was a problem in their community, many stated that it was a problem in other Native communities.

Smoking and other drug use during pregnancy (particularly marijuana and over the counter drugs) were also perceived by the many of the respondents to be a problem. The **use of cocaine** during pregnancy was either not perceived to be a problem or else participants did not know whether it was a problem.

Education processes believed to be most effective with pregnant women were:

- one-to-one counselling,
- videos
- small group therapy,

- support groups, and
- testimonials (video or other).

The FAS educational resources currently available were believed by most respondents to be inadequate or inappropriate. The primary weakness with the current resources are:

- literacy level is too high
- not culturally appropriate
- not visual enough, i.e. too "wordy"
- do not reflect the reality of the client (i.e. posters depicting "couples" are inappropriate for use with single mothers)

Appropriate educational resources should have the following characteristics:

- target a range of women
- be culturally specific and locally relevant (i.e. reflect traditional Native cultures and values, use Native models, etc.)
- be primarily visual (use of color, texture, pictures vs words)
- be written at Grade 7 or lower literacy level
- use testimonials by individuals perceived to be similar to the client, and therefore more credible.

Suggestions for a comprehensive FAS prevention program included (these are clearly applicable to general FS prevention):

- the need for school programs at the high school level and earlier
- a focus on increasing public awareness of the long-term and serious consequences of FAS.
- the need for raising physicians' levels of awareness re: FAS, the need for prenatal identification of risk, and the need for early diagnosis and prompt intervention
- development of peer support programs
- community-wide awareness workshops
- development of information packages for resource workers, young mothers, pregnant teenagers
- training for Native resource people

5.3.2 Summary

In general, most of the Native health care providers interviewed were not involved in anything more than superficial FAS prevention efforts (and no FS prevention), with the exception of the POPs coordinators. Generally, the responses reflected a limited understanding of FAS and fetal syndromes, particularly with respect to

prevention. Drug and Alcohol counsellors and CHRs felt that they did not have enough information or training to effectively do FAS prevention education, despite the fact that many of them believe FAS to be a problem in their communities.

Smoking and other drug use was not perceived to be as big a problem as alcohol in most communities, however, it was still considered an important concern by most respondents. Cocaine use was not believed to be commonly used by pregnant women.

Almost all participants felt that the available education resources were inappropriate and would like to see culturally specific education materials developed for use with pregnant women in their communities. The participants assessment of the available education resources is consistent with our evaluation of the materials described in section 5.4.1 below.

School based prevention programs were seen to be an essential component of a comprehensive prevention program. Other important elements of such a program include physician education, training for community resource workers (i.e. train the trainers), the development of culturally specific education resources, and public awareness strategies.

5.4 Review of Existing Fetal Syndromes Education Resources

Resource materials are an important component of any prevention program. A broad range of prevention education materials and resources were reviewed, with the specific intent of indentifying the strengths and weaknesses of these resources for use in Native commmunities. Materials currently in use in British Columbia, the Yukon, Saskatchewan, Washington State, Alaska, and various other places in the United States were considered in this review. Materials were identified in discussions with key informants and by contacting various prevention agencies in Canada and the United States. Audiovisual resources were identified with the help of the Medical Services Branch Audiovisual Resource Centre, and in the Oromocto Fetal Alcohol Syndrome Education Package and Resource Kit (refer to Program Review, Appendix B). Again, the emphasis is on alcohol prevention resources because few materials are available which target other substances. A few exceptions are noted.

5.4.1 Review of Fetal Syndromes Prevention Education Print Materials

Appendix E provides a review of a wide variety of available fetal syndromes education print materials. Each resource is described in terms of its target group, content, method of presentation, strengths and weaknesses. The major strengths and weaknessess of these materials are summarized below. In addition, a number of recommedations to guide the development of education materials are presented.

In general, there are some excellent educational print materials available. There are, however, fewer resources available focusing on the use of drugs (other than alcohol) during pregnancy. The good materials, as noted in the review, could be readily adopted or adapted for use in British Columbia. Despite the existence of a few good resources, much of the material has serious shortcomings.

The primary problems with the existing educational materials are:

1. A tendency to be paternalistic with a "talk down to" type of approach, especially the low-literacy materials.

2. A tendency to be negative - i.e. focus on the DON'Ts rather than the DO's.

3. Materials encourage dependence on health care personnel rather than fostering independence (i.e. they are not empowering).

4. A limited range of literacy levels.

5. Materials do not generally present positive alternatives to drug and alcohol use

6. A tendency to take a "blaming" approach. While this may be inadvertant, this approach may induce feelings of guilt and thus be counterproductive.

7. Information is not relevant to the local region or the population. There are few materials appropriate for specific use in Native communities.

8. In some cases, there is good information on the problem, but no information on where to go for help.

9. Where suggestions for help are included, there is a tendency to emphasize the role of the physician. Many at risk women may be reluctant to visit a physician, so it would be better to include references to other professionals.

10. The resource packages generally provide a good range of material but don't usually include much information on ideas for community-based, community-wide prevention strategies. The emphasis tends to be on one-to-one interactions.

11. An emphasis on alcohol to the exclusion of tobacco and other substances.

Recommendations for the development of educational print materials follow obviously from the problems identified above.

An effective print resource should have the following characteristics:

1. A positive, empowering approach which emphasizes what women can do for themselves and their babies.

2. Demonstrates respect and caring. It is not blaming and therefore not guilt inducing.

3. The literacy level should be appropriate for the target population.

4. The message has been focus tested for appropriateness with the target population.

5. Provides realistic suggestions for alternatives to tobacco, drug and alcohol use.

6. Provides information on where to go for help, including health care providers other than, or in addition to a physician (e.g. CHR in Native communities).

7. The same message be developed in a range of formats for different target groups.

8. The information is locally and culturally relevant.

9. The resource should be as succinct and short as possible.

5.4.2 Review of FAS Prevention Audiovisual Resources

A number of FAS/FAE audiovisual resources, primarily films and videotapes, were reviewed in terms of the target audience, content, strengths and weaknesses, and appropriateness for use in Native communities (refer to Appendix F). No AV resources were located which focused on substance use outside the context of alcohol use. In general, there are very few audiovisual resources appropriate for use in Native communities. Only two were produced that specifically target the Native population and which we would also recommend: Something to Celebrate, and FAS: The Preventable Birth Defects. In addition, the 20/20 production is also recommended for use in Native communities, although not specifically produced for that purpose. These, however, are not without their weaknesses.

Many of the resources reviewed are now outdated with several inaccuracies. Few of the videos focus specifically on prevention with concrete positive suggestions for women who might be drinking. A common theme is the use of a "blaming"

approach, which is likely to be inadvertant but nonetheless counterproductive. Some of the films are subtly or overtly rascist.

A good audiovisual resource for use in Native communities would include the following components:

1. Historical, social and cultural context of alcohol and substance use in the Native population.

2. Discussion of fetal syndromes (not just FAS) as a B.C. health concern that can occur whenever alcohol and drugs are abused (i.e. not just a Native problem).

3. Etiology, epidemiology and physical characteristics of FAS/FAE and other fetal syndromes in a clear, straightforward, non-technical presentation.

4. A postive empowering approach emphasizing the positive things a woman can do for herself and her baby.

5. The role of the community and other support networks in prevention. A woman often drinks, smokes or uses drugs in the company of others, therefore it is important that the message reach the spouse, family and community.

6. Native actors, preferably real-life interviews and/or testimonials incorporated with Native mother or parents and a Native child or children.

7. Individual and community strategies for primary, secondary and tertiary prevention.

8. Visual, fast paced, stimulating and motivating.

9. Emphasis on the long-term, lifelong nature of the problems.

10. Realistic presentation that, while there is no known safe level and it is best to abstain, there is a dose-response relationship between alcohol use and FAS. Recent literature emphasizes the danger of overstating the risk. Exaggeration can decrease the credibility of public health warnings and cause parents of abnormal children to feel guilt.

11. Emphasis on the fact that FAS does not only occur in alcoholic women. Discussion of drinking patterns that may result in FAS (i.e. binge drinking).

In general, there are few audiovisual resources currently available for use in Native

communities. The development of new resources which are B.C. specific and target a range of audiences are needed. However, until such resources can be developed, there are three videos which could be utilized for education purposes with a Native audience.

5.5 Summary and Conclusions from Fetal Syndromes Needs Assessment and Program Review

There are currently no comprehensive fetal syndrome prevention efforts on-going in British Columbia. The only specific fetal syndrome prevention activity currently taking place is the Pregnancy Outreach Project. However, the scope and extent of prevention education within the context of each individual POP program may vary from time to time, and of course varies considerably between POP programs. Access to POP programs is limited because there are only 8 communities across the Province in which a POP program is operating.

Recent presentations by Native groups to the Royal Commission on Health Care and Costs have identified alcohol and other drug use during pregnancy as a major health concern. The majority of respondents in our Native health care worker survey (66 percent) corrorated this. However, most of the Community Health Representatives (CHRs) and alcohol and drug counsellors did not feel adequately prepared to conduct fetal syndromes prevention education. Current training for CHRs does not include specific preparation for fetal syndromes prevention.

All of the respondents perceived the existing fetal syndromes education resources to be inadequate and inapproprate for use in Native communities. The primary concern with the resources was that materials were not culturally appropriate or were written at an inappropriate literacy level. Our review of the programs and education resources generally supports this view, although we did identify three audiovisual resources which we would recommend for use by Native groups. However, new audiovisual resources are needed which meet the criteria outlined in Section 5.4.2 above and which emphasize the prevention of substance abuse other than alcohol. Testimonials are perceived by many of the Native health care workers as an effective education device. Videotapes provide an effective medium for for this type of communication.

There are some Native specific resources developed in the U.S. for American Native groups, which could be used as models for the development of materials here in B.C. However, we agree with the observation that no locally relevant Native specific resources currently exist. In addition, we noted that there are few resources which do not rely on a written presentation. Even low literacy print materials are inappropriate for people who cannot read at all.

The health care workers also suggested that appropriate resources need to target

a range of women and to reflect the reality of the client. The relative lack of any British Columbia specific prevention resources supports this observation. In addition, we recommended that an effective print resource should be positive, not blaming, provide concrete suggestions for positive alternatives, and present information on where to go for help.

Suggestions for comprehensive programs by the Native health care workers included the need for school based programs, physician awareness about FS, the development of peer support programs, community-wide awareness workshops, and education resource packages. Currently, none of this is occuring in Native or non-Native communities in any kind of systemantic way. While there are plans to incorporate drug and alcohol abuse prevention programs into the school curriculum, there are no programs which specifically deal with fetal syndromes prevention.

The need to raise physician awareness of the issue was also supported by the literature and was stressed by many of the key informants. Early identification is critical and the health care professional who is most likely to see clients early enough in pregnancy is the physician. There were few fetal syndromes education resources for physicians in our program review, and certainly no British Columbia examples. The Manitoba Medical Association FAS prevention program (refer to Program Review, Appendix B) represents a positive move in this direction and, depending on the outcome, could be adapted for implementation in B.C.

Key informants raised the issue of the need for an integrated approach to prevention which targets women at all risk levels and utilizes a broad range of strategies. This was supported by the literature and by our program review. Peer support, family and community support were consistently mentioned as being critical factors in successful prevention programs. These issues were also raised by the key informants and the health care workers.

Finally, the need for community-based and community development approaches to fetal syndromes prevention was stressed continually by key informants, in the literature and by our program review. The fact that this was not mentioned by many of the health care workers reflects their lack of training and preparation for fetal syndromes prevention.

6.0 CHALLENGES FOR PREVENTION OF FETAL SYNDROMES IN BRITISH COLUMBIA

Throughout this review, a number of issues have been raised which present challenges for developing and implementing effective fetal syndromes prevention programs in this province. This section presents a review and discussion of the major challenges.

1. **The primary challenge for fetal syndromes prevention is identifying at-risk women early enough in pregnancy to effectively intervene.**

There are three factors which present difficulties for early identification and intervention with at-risk women:

a) **At risk women are less likely to seek early prenatal care.**

Women at risk for adverse pregnancy outcomes due to alcohol and drug use are less likely to seek prenatal care early in their pregnancy. Although early medical care for these women is important, many at-risk women will not seek the care of a physician. Mechanisms to encourage and support women to seek early prenatal care are important to develop. It may also be prudent to develop alternative and more accessbile entry points to the health care system for these women. This may be particularly important for Native women living on reserves in isolated locations where there is limited access to health care facilities and medical care.

b) **Even when women do access prenatal care early in their pregnancy, the probability that a drinking or drug use problem will be identified is low.**

The literature indicates that physicians are either unwilling or unable to identify risk behaviour related to alcohol and drug use. It may be that the stigma attached to such use during pregnancy makes it uncomfortable for physicians to deal with. It may also be due to the fact that until recently, there has been no training in medical schools about risk identification and counselling techniques for dealing with these problems.

c) **There are few community health programs which target women early enough in pregnancy to make an important difference.**

Prenatal classes are not generally held until late in the second or early in the third trimester of pregnancy. At this point, much damage can already have been done. Early bird pregnancy classes are held in most areas of the province, but generally involve only a one-shot, two to three hour lecture which covers a range of topics other than nutrition and substance use during pregnancy. Furthermore, there appear to be no standards for the implementation of prenatal programs and there has been no comprehensive evaluation of outcome. One of the reasons for the recent transfer of responsibility for general prenatal education from provincial health units to community based agencies was to allow for greater emphasis by health units on the at-risk population. Accessing the at-risk population is critical to ensure appropriate delivery of prevention services. It is not clear to what extent this has been achieved.

Even the POPs programs, which have a mandate to deal with prevention of fetal

syndromes, do not receive client referrals early enough. The average length of gestation at intake is 14 weeks, which is already into the second trimester of pregnancy. While a reduction in drinking, smoking or drug use at any time during pregnancy has been demonstrated to have positive outcomes, it is essential that women are identified and intervention begun as early as possible in pregnancy. Earlier identification by physicians and other health professionals would facilitate earlier referral to POPs and other intervention programs.

Methods of identifying, targeting and reaching women very early in the first trimester of pregnancy need to be developed.

2. **Health professionals are not adequately trained in risk assessment and counselling techniques for women who drink and use drugs during pregnancy.**

Training of health professionals in risk assessment and counselling/health behaviour change techniques should ideally be part of the core curricula. Mechanisms to implement such training in the basic education of all health professionals who care for pregnant women are essential. Continuing education programs must be developed for health professionals already working in the field.

3. **Even when identification of problem drinking and drug use does occur, there are few resources for treatment and referral, particularly for Native women.**

The special needs of pregnant women are not adequately considered in the currently available alcohol and drug treatment programs. It is particularly difficult for women with children to leave their communities to attend a treatment program. Women who are pregnant and drinking need immediate treatment. The waiting lists for some treatment facilities makes this impossible. Furthermore, the inextricable links between alcohol/drug use and sexual abuse, sexual assault and family violence, make the existing co-ed treatment inappropriate for many women.

4. **There is currently an under-reporting and inadequate identification of children with fetal syndromes in British Columbia.**

Although there are no hard data to support this assertion, the perception of respondents to our health care worker survey, is that there are many FAS children in communities across B.C. that have not been identified or diagnosed. The perception is shared by members of the FAS Resource Group, and staff of the Infant Development Program.

Early identification of a fetal syndromes child is important, not only to maximize the potential of that particular child, but to prevent the birth of a second affected child by the same mother. The mother of one fetal syndromes child is at very high risk

of giving birth to a second affected child. An FAS registry has been suggested as one method of facilitating identification and follow-up of FAS children and their mothers.

There are many implications of a program to improve the rate of FAS diagnosis. Identification of an FAS child sets up the expectation that the needs of these children will be addressed. Tertiary prevention for these children can be very expensive, although early identification and intervention may prevent the serious amd more expensive consequences that are likely to occur without intervention. This issue, because it is beyond the scope of this report, has not been adequately considered, but represents a critical concern.

5. **Federal/Provincial Jurisdictional Issues**

The issue of federal/provincial jurisdiction for Native health has been argued for many years. This presents a significant challenge for the development of prevention programs for the Native population. There appears to be a general unwillingness, on the part of various levels of government, to accept responsibility for a variety of Native health care issues. The distinction between Status and non-Status, on-reserve and off-reserve populations appears to lie at the heart of this debate. The result is that many essential programs and services for Native people are simply not provided. It is essential that the Province work collaboratively with the federal government to resolve these issues.

6. **Prevention funding has traditionally been a low priority in the face of competing needs for treatment.**

Although the prevention of even one occurrence of a fetal syndrome could save the Province over $1 million, there has been limited funding for prevention. In these days of shrinking health care dollars and rising costs, there is a need to strike a balance between the treatment of existing illness and the prevention of future illness. This will necessitate some difficult political decisions. Historically, prevention funding has represented an insignificant proportion of provincial and federal budgets.

If no new dollars are available for prevention, a critical re-examination of spending priorities within existing budgets may be necessary. Policies and decisions concerning programs must be based upon adequate evaluation data. Funding for programs which have not been able to demonstrate their effectiveness may need to be abandoned in favour of those which have been shown to make a difference. New program development must follow an accepted planning process based on the theoretical determinants of the health problem and utilize the most effective, state-of-the-art strategies. This is most likely to result in the desired outcome. Too many programs in the past have lacked a solid theoretical foundation and an

adequate evaluation base.

7. **Intra and Inter-Ministerial Jurisdiction**

The issue of fetal syndromes prevention falls within the jurisdiction and mandate of many branches within the Ministry of Health and of several other Ministries. Because of the diffusion of responsibility, there is often an inadvertent lack of communication, coordination and collaboration within and between Ministries. The outcome is a very inefficient use of resources and the lack of appropriate and necessary programs.

This is particularly evident with the issue of fetal syndromes prevention. Within the Ministry of Health alone, there are at least 5 branches that should be involved in the planning process: Health Education, Native Health, Family Health, the Office of Health Promotion, and Policy, Planning and Legislation. Other Ministries that are affected include Labour and Consumer Services (ADP), Native Affairs, Education, the Attorney General, and Advanced Education, Manpower and Training. A mechanism to facilitate communication, collaboration and coordination is essential if an efficient and cost-effective prevention strategy is to be developed.

8. **Native Rights Movement**

There is currently disagreement among Native groups about the best way to deal with issues such as the prevention of fetal syndromes and alcohol/drug abuse. It will be a challenge for Government to remain open to and respond sensitively and appropriately to the divergent expression of need by the Native community.

The move to self-government and increasing local control by Native communities over the administration and delivery of health services raises many issues around the role and responsibility of Government. Increasingly, Government may be required to take on a supportive and non-directive role as more and more Native communities assume self-administration. However, different communities are in different stages of development in this process which may require more Government input and support in some communities than others.

Collaboration with Native communities in the development of prevention programs is essential. Community-based, community-directed and community-wide strategies for prevention will be the hallmark of successful programming in the future. Mechanisms for Government to support and facilitate this process are essential.

9. **Increasing recognition of the fact that many of the major determinants of health status lie outside the domain and control of the health care system.**

The Epp framework "Achieving Health for All" helped to raise the conscicusness of health professionals and the public about the importance of public policy in affecting the overall health status of the population. Clearly, there are many conflicting interests between those concerned about health issues and others concerned with economic development, for example. This raises serious ethical and moral issues for different branches of Government.

Issues around the prevention of alcohol and tobacco use are a good example of this dilemma. Taxes from sales of alcoholic beverages and tobacco generate substantial income for the Province. The more alcohol and tobacco sold, the more income for Government. In tough economic times, the dilemma becomes more difficult. However, the more alcohol and tobacco sold, the greater the likelihood of higher rates of related morbidity and mortality. The issue of legislative controls and mandatory labelling, while potentially an important preventive measure, will invoke strong opposition from industry.

The Ministry of Health, as the single largest Ministry with the largest budget, is not without influence. Strong pressure from the Ministry may be effective in influencing policy decisions by other Ministries that could possibly result in a substantial reduction in the incidence of fetal syndromes. This is clearly a major prevention challenge.

7.0 SUMMARY AND CONCLUSIONS

Fetal Alcohol Syndrome, alcohol related birth defects and other fetal effects due to the use of alcohol, tobacco and other drugs during pregnancy presents a significant public health problem in this province. While there is some debate on the exact incidence and prevalence of these conditions, we do know that FAS, for example, is the single greatest cause of preventable mental retardation in this country. While Fetal Syndromes occur in all racial groups, the demographic profile of the Native community (i.e. a very young population, a high fertility rate, and higher reported rates of alcohol and tobacco use) puts Native women at high risk for adverse pregnancy outcomes.

The economic burden to the Province in lifetime care costs for fetal syndromes children born in any one year is estimated at approximately half a billion dollars. Fetal syndromes can have devastating consequences for the affected infants and for their families. Children with FS have lifelong problems that are not resolved with time. They are more likely to suffer from abuse, neglect and a host of other problems.

A review of FS prevention programs and educational resources was conducted to provide the basis for the development of a series of recommendations for fetal syndromes prevention in British Columbia. In addition, Native health care workers providing direct services to Native clients in British Columbia were surveyed to determine their perceptions of fetal syndromes prevention needs in their communities.

FAS and other fetal syndromes were considered by the respondents to be an important health concern. The majority of Native health care workers surveyed for this project expressed the belief that FAS was a health concern in their communities. However, most of these workers indicated that they did not feel adequately prepared to deliver fetal syndromes prevention education in their position as health care workers. Existing fetal syndromes education resources are perceived to be inadequate and inappropriate for use in Native communities.

A number of challenges to the development and implementation of an effective prevention strategy in the province were presented of which the most important is the difficulty in identifying at-risk women early enough in pregnancy in order to effectively intervene.

Fetal Syndromes are completely preventable. There is evidence that by identifying and intervening with women early in pregnancy, adverse fetal outcomes can be avoided. Primary prevention efforts are also critical to prevent young women from developing risk behaviour long before pregnancy occurs. However, it is clear that there can be no "one size fits all" prevention program or strategy. Prevention activities must be consistent with the priorities, values, world view, and ways of communicating that exist within each community (U.S. Department of Health and Human Services, 1990).

The determinants of alcohol and other drug use and abuse are complex and multidimensional and occur within a cultural, social and economic context. Factors such as value systems, cultural norms, beliefs and attitudes, provincial policies and programs, laws, education, social structures, economic conditions, and many other things contribute to the development of alcohol and drug problems. Effective prevention strategies must address these complex factors.

The prevailing view regarding effective prevention is that it can best be achieved through multiple strategies that address the unique characteristics, cultural diversity, and structure of each individual community (U.S. Dept. of Health and Human Services, 1990). As such, communities themselves are the most important agent of social change, drawing on their own unique strengths to foster growth and create a climate of health.

The approach to prevention taken in this paper is based on the fundamental belief that the community itself must take ownership of the problem and direct the change process. The role of Government should be facilitative and supportive rather than directive. With this in mind, recommendations for the prevention of fetal syndromes in British Columbia are presented below.

8.0 RECOMMENDATIONS

1. Develop a comprehensive Provincial Strategy for the prevention of Fetal Syndromes which focuses on the entire population of the Province. Targeting of specific at risk groups (i.e. Native population) and the implementation of specific strategies should occur within the context of the larger, overall Strategy.

2. To facilitate this process, inter-Ministerial collaboration is necessary. An Inter-ministerial working group should be established. Ministries that should be involved in the planning process and in funding the activities include:

   Ministry of Health
   - Native Health
   - Family Health (Nutrition Branch and Public Health Nursing)
   - Office of Health Promotion
   - Communications and Education
   - Policy, Planning and Legislation

   Ministry of Labour and Consumer Services
   - Alcohol and Drug Programs
   - Liquor Distribution Branch

   Ministry of Native Affairs
   - Social Policy Branch

   Ministry of Social Services and Housing
   Ministry of the Attorney General
   Ministry of Education
   Ministry of Advanced Education, Training and Technology

3. Collaboration with other levels of Government would also be useful, particularly the Medical Services Branch and the Health Promotion Directorate of Health and Welfare Canada. Initiate discussions with these groups to identify common goals and objectives and potential opportunites for collaboration on the issue of fetal syndromes prevention.

4. Within the comprehensive strategy, the special needs of high risk groups must be addressed. The Native population represents one at-risk group. To effectively address the needs of this group, a Native Advisory Group should be established. The role of the group would be to facilitate this process and to guide program and materials development to ensure that they are sensitive to the needs of the

community.

The advisory group should be comprised of 6 to 8 members of the Native community who represent a broad cross-section of interests. Individuals with expertise in the following areas should be considered for membership:

- community leadership
- community resources
- community-at-large
- general Native issues as well as Native health issues
- health professions
- community development
- prevention program planning and evaluation
- Addictions and alcohol/substance abuse
- Fetal alcohol syndrome

5. Establish funding for demonstration and evaluation prevention projects for Fetal Syndromes at the community level. This will serve to develop and establish appropriate modes for FS prevention in British Columbia. Currently there are few good models and the data are lacking to establish them.

   Proposals should be solicited from communities. Proposal selection should be based on the guidelines noted in Section 4.4 and Appendix B for effective prevention programs. A designated proportion of the funding should be set aside specifically for high risk groups, i.e. Native communities, inner city communities, etc.

6. DEVELOPMENT OF EDUCATIONAL MATERIALS

   - develop a Fetal Syndromes community resource package for use by front line care providers
   - consider collaborating with other Ministries and the Federal Government in funding the development and production of this package. This will eliminate duplication of efforts, and save money for individual branches while ensuring the development of a "better" package due to higher levels of funding
   - much of the information in the package will be generic and applicable for use in any community, however, variations on the package should be developed for specific at risk-groups, i.e. Native communities
   - the Native Advisory group should provide input on the development of the Native specific package
   - the resource package should include (but not necessarily be limited to):
     - background information on Fetal Syndromes for community resource persons and front-line care providers

- a broad range of strategies for implementation of prevention education at the community level
- information on networking and strategies to involve a variety of community agencies and social systems
- educational materials for distribution in the community, targeting various groups (e.g. posters, pamphlets, brochures, fact sheets, buttons, fridge magnets, mugs, etc.). This may involve the development of new materials, but may also include the use of existing resources.
- where to go for help: who to talk to, how to access resources
- list of resources with evaluative information and recommendations

- the development of educational materials should follow the guidelines outlined in Section 5.4.1 above.
- fund the development of a videotape for inclusion in the resource package, which is specific to the needs of the B.C. population. Consider collaborating with the Medical Services Branch of Health and Welfare Canada, the government of the Yukon Territories, and the Government of Alberta in the development of the videotape.

7. Collaborate with the federal and other provincial governments to establish a Clearinghouse, (modelled after the Canadian Council on Smoking and Health clearinghouse) for information on alcohol and substance abuse prevention in general, and Fetal Syndromes prevention in particular. The purpose of the Clearinghouse would be:

   - to establish a reference and resource data-base,
   - to centralize and house resources and education materials,
   - to ensure ready accessibility to information for anyone in the province
   - to serve a networking function
   - to develop mechanisms of cost-recovery for the distribution of materials and resources particularly for out-of-province requests
   - the clearinghouse may also be the appropriate agency to establish and house a FS registry.
   - with appropriate staffing, the Clearinghouse coordinator could assume an important role as community educator, and be involved in training community resource persons.

8. Establish a telephone Hot-Line for dealing with concerns about alcohol, tobacco and substance use during pregnancy. This should be a dedicated line, staffed by trained individuals. The hot-line could easily be coordinated and operated from the Clearinghouse.

9. Implement a Province-wide public awareness campaign.

   - Consider working with the BCMA to implement the Manitoba Medical Association strategy. This could reduce costs for the Province and involve an professional group that has been identified as critically important in prevention efforts. Other professional groups could also be involved: e.g. RNABC, BCHA. The public awareness campaign should go beyond the scope of the Manitoba campaign, but could be conducted in conjuction/partnership with the professional organizations (BCMA, RNABC, others).

   - Within the scope of the broad public awareness campaign, targeting of specific at-risk groups at the community level should occur.

   - Establish the week following Mother's Day, 1992 as Fetal Syndromes Prevention Week. This would be the framework for the kickoff of the public awareness campaign, which can be modelled after the Virginia campaign but adapted to the B.C. situation. Involve Native communities in the campaign, where local communities determine and direct activities in their own areas to increase awareness of the issue. The Native Advisory Group should guide the planning process for this component of the campaign. A community resource package can be prepared for distribution to community groups and agencies to aid in the development of the community specific campaign.

10. Legislate the use of warning labels on all alcohol products.

11. Legislate point-of-sale education in bars, restaurants, lounges, etc. A first step toward the implementation of this recommendation, is to work with owners/managers of vending establishments to voluntarily post information on the hazards of alcohol consumption during pregnancy.

12. Investigate the implications of raising the drinking age to 21 years. This has been implemented in all states in the U.S. and has had a significant impact on alcohol consumption in general, drinking and driving, and alcohol related traffic accidents.

13. Investigate the implications of price increases for alcohol products.

14. Support the development of training modules for front line care providers (e.g. CHR's, NNADAP workers, alcohol and drug counsellors). Collaborate on this with Medical Services Branch, Health and Welfare Canada.

15. Work with the Ministry of Education to ensure that appropriate FS prevention programs are incorporated into the Learning for Living curriculum at the secondary level. Ensure that there is an FS component in the drug and alcohol education being implemented at the elementary level.

16. Work with the Ministry of Advanced Education, Training and Technology and the professionals schools of medicine, nursing, etc. to ensure adequate training in alcohol and substance abuse education in general, and with specific reference to the impact of use during pregnancy. Training should include risk identification, counselling and referral, and prevention program planning, implementation and evaluation. This should be incorporated into the core curricula of these programs.

17. Work with the professional schools (including UBC First Nations Health Care Professions group) and professional Associations to develop continuing education workshops on alcohol and substance abuse prevention in general, and FAS/FAE prevention in particular.

18. Ensure the provision of a specified number of spaces in alcohol and drug abuse treatment centres, specifically for pregnant women.

19. Develop inservice education programs for alcohol and drug abuse treatment centre workers on FS and the specific needs of pregnant women.

20. Establish more frequent intake of women only cohorts for alcohol and drug treatment.

21. Develop an Inter-Ministerial Protocol for the early identification (first trimester of pregnancy) and management of at-risk pregnant women.

22. Continue to fund existing Pregnancy Outreach Projects. Expand the POPs program to include more communities across the Province, including on-reserve Native communities. Develop in-service training workshops for POPs staff to enhance their skills in risk assessment and prevention education related specifically to FS prevention.

23. Establish provincial standards, guidelines and objectives for prenatal education at various stages of pregnancy.

24. Evaluate the effectiveness of existing prenatal programs utilizing the newly developed standards, guidelines and objectives as a framework.

25. Develop a comprehensive perinatal wellness program for British Columbia which incorporates the FS prevention strategy as one component of this overall program.

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APPENDIX A

FETAL SYNDROMES PREVENTION PLANNING MODEL

FETAL SYNDROMES PREVENTION PLANNING MODEL

INTERVENTIONS TARGETING THE HOST

	Preconception	Prenatal	Intrapartum	Postpartum
Low Risk	General Public information for women of childbearing age School curricula Worksite preconception programs	Prenatal literature and education focusing on substance use in pregnancy Public awareness through media Prenatal care Education focusing on abstinence	Education of new moms in hospital by nursing staff Focus on substance use during breastfeeding Education by physicians	Public information for women of childbearing age Prenatal home visit by PHN Provision of info re: substance use to new mothers
Moderate Risk	General public info re: no known safe dose Programs emphasizing alternatives to tobacco, drug and alcohol use for teens and young women who are not current users	Assessment of substance use during pregnancy Education on no known safe level Emphasis on reducing consumption and alternatives Public info through media Prenatal care	Community development programs Identification of users Education focusing on decreasing consumption post-partum	Utilization of substance use history to identify potential problems Post-natal home visit to identify substance use
High Risk	Identification of at risk girls and young women by health professionals, schools Counselling and referral	Identification and referral of substance abusing pregnant girls and women Counselling services Treatment programs	Referral of substance abusing women identified while in hospital to give birth Education for professionals re: referrals for affected child	Referral of mothers of FS child for counselling and treatment to prevent second FS child Referral of affected children Post-natal visit identification

FETAL SYNDROMES PREVENTION PLANNING MODEL

INTERVENTIONS TARGETING THE AGENT

	Preconception	Prenatal	Intrapartum	Post-Partum
Low Risk	Legislation re: warning labels Point of sale education Pricing Restrictions on alcohol and tobacco advertising Community action to reduce access Restrictions on location of sales Restriction of tobacco sales to minors	Same as for preconception	Same	Same

Interventions for Moderate and High Risk groups are the same as for those targeting low risk groups. Basically, legislation and interventions to reduce access to alcohol will have an effect at every risk level, and across the Maternal child continuum

FETAL SYNDROMES PREVENTION PLANNING MODEL

INTERVENTIONS TARGETING THE ENVIRONMENT

	Preconception	Prenatal	Intrapartum	Post-Partum
Low Risk	General Public information through the media School curricula Dry Grads Health professions curricula Community development	Public awareness targeting spouses and families of pregnant women Professional education re: effects on fetus Prenatal literature Prenatal classes Community development	Professional education re: effects on fetus In-hospital education re: effects of substance use on breastfeeding infant Community development	Public information Education for post-natal providers Education for families Community support groups Peer support programs Post-natal home visit Community development
Moderate Risk	Public awareness School curricula Health Professions curricula Information directed at teens, and young men and women Education directed at young married men Marriage preparation courses Community development	Public awareness for women and partners Risk identification training Availability of counselling resources in community Community development	Risk identification In-hospital education As above	As above
High Risk	Identification and referral of problem families Community support services for families Community development	Community involvement in identification of risk behaviour Public awareness Availability of referral networks Community development	Training of professionals for risk identification In hospital networking with referral sources Community development	Development of community supports for affected families Community development Peer support groups Community development

APPENDIX B

REVIEW OF COMPREHENSIVE FETAL ALCOHOL SYNDROME PREVENTION PROGRAMS

1. **FETAL ALCOHOL EDUCATION PROGRAM**
Boston University School of Medicine

Weiner, L., Rosett, H. & Mason, E. (1985). Training Professionals to Identify and Treat Pregnant Women Who Drink Heavily. Alcohol Health and Research World, 10(1), 32-35.

TARGET:

- health professionals who deal with pregnant women, e.g. physicians, nutritionists, nurses, social workers.

DESCRIPTION:

- designed to improve the skills of health professionals in the treatment of problem drinking during the prenatal period.
- Utilizes Alcohol and the Fetus: A Teaching Package, consisting of 81 slides and a descriptive manual, based on the literature and the authors' experience with the identification and treatment of pregnant women who drink heavily.
- The major focus of the program is to present clinical strategies for identifying and treating women at risk.
- Methods to identify heavy drinking during pregnancy are provided.
- Techniques for counselling pregnant women are reviewed.
- A critical goal of treatment is to build self-esteem in the client.
- emphasis is on a positive, hopeful message since provocation of guilt and self-criticism are intolerable to many women and may lead to increased consumption.

IMPLEMENTATION:

- in the first year, 55 training sessions were conducted reaching over 1700 health professionals
- to extend the efforts, a "train the trainer" approach was taken and 34 inservice educators were recruited from a variety of disciplines.

RATIONALE:

- A major weakness in the efforts to prevent FAS is the fact that clinical intervention with women whose offspring are at greatest risk for FAS has been minimal.
- Media campaigns have limited effect on problem drinkers.
- pregnancy is a time when most women are particularly motivated to improve health-related behaviour.
- programs aimed at reducing drinking among alcohol abusing women have been successful with concomitant reduction in adverse pregnancy outcomes.
- the attitudes of professionals toward alcohol abuse by pregnant women is problematic and need to be changed.
- Incorporation of treatment strategies into routine prenatal care represents an effective, low-cost method of preventing fetal alcohol syndrome.

2. **NATIONAL INDIAN FETAL ALCOHOL SYNDROME PREVENTION PROGRAM**
All Indian Pueblo Council,
2401 12th Street, NW,
Albuquerque, New Mexico

REFERENCES:

Prugh, T. (1985). FAS Among Native Americans: Detection and Prevention. Alcohol and Health Research World, 10(1), 36-37.

May, P.A. & Hymbaugh, K.J. (1989) A Macro Level Fetal Alcohol Syndrome Prevention Program for Native Americans and Alaska Natives: Description and Evaluation. Journal of Studies on Alcohol, 50, 508-518.

TARGET:

- Community Resource people who are trained as Prevention Specialists

- Primary Target groups for the Prevention Specialists:
  1) 4th and 5th graders,
  2) secondary school students,
  3) women who are pregnant for the first time, and
  4) the community at large.

- These particular populations were defined as target groups because: a) of the need to emphasize prevention in youth, b) the majority of the Native American population is under 22 years, and c) most FAS/FAE babies are born to women over 25 years.

- Thus, the purpose was to target people before dangerous or destructive drinking patterns had developed (i.e. primary prevention).

- Secondary Target group: Women who have already had one FAS/FAE child.

DESCRIPTION:

- focus has been on developing and delivering prevention training services and materials for use by tribal groups throughout the United States.

Key Elements:

1. Training Trainers

- to obtain the widest possible dispersal, the program concentrates on training trainers (both clinicians and prevention specialists).
- the prevention trainer's first mandate is to disseminate information about FAS and FAE to their respective communities and to train others to do the same
- training was accomplished in a 2 day, centralized workshop, which covered

clinical and educational interventions, prevention and programming issues.

- regional FAS consultants were established to serve as a link with local and regional efforts, and the consultants continued the training process.

2. Resource Development

- 10 pamphlets, 6 posters, 16 fact sheets, and a basic slide set (20 slides and narrative) were developed as the core elements of FAS education and training. Each of these elements was keyed toward one of the four primary target groups listed above.
- the program materials were also developed to attract the attention of specific Native American cultural groups (e.g. Plains tribes, the Navajo, Alaska Natives, Pueblo tribes, and contemporary/acculturated Native Americans.
- a set of suggested curricula was developed to ensure efficient use of these materials. The curricula focused on each of the four target groups and listed several training options for each.
- the program office also operated as a resource centre by developing and stocking a variety of audiovisual materials (e.g. pamphlets, posters, reading lists, selected articles, press releases etc.)

3. FAS Identification

- FAS/FAE recognition training was also provided in the belief that case finding is important not only for treatment referral, but for further prevention, since approximately half of all mothers bearing affected children produced multiple FAS babies.

EVALUATION:

- close associations with other FAS programs were established
- several tribes founded and funded their own programs with support from this program
- many requests for technical assistance were met
- evaluation results of knowledge gained indicate that the local trainers had substantial success in imparting FAS information to prenatal groups, community groups and school children.
- knowledge was retained by these groups over time, and there may have been some diffusion of knowledge among peers in local communities.

- the only outcome measure was knowledge, which limits the ability to determine program effectiveness
- the unknown level of incidence and prevalence makes it difficult to determine whether any impact on an actual reduction in FAS incidence was achieved.

RECOMMENDATIONS:

The project was not able to demonstrate a decreased incidence in the overall rates of FAS/FAE, due primarily to the difficulties inherent in determining initial incidence and

prevalence. While there were some positive outcomes as noted above, several recommendations were made for improvements.

1. There must be reinforcement and reward for continuous performance of FAS prevention activities, i.e. special job related rewards written into employee performance standards.

2. The selection of local and area trainers was left up to local officials and did not always result in the best selection. More central control over selection would minimize this.

3. Turnover of trainers was a problem. Could be dealt with by contractual commitment, or by training more individuals in each location.

4. Baseline FAS screening would have been extremely motivating in the initial phases of the project, and would have enabled a stronger focus on secondary and tertiary prevention.

5. Secondary and Tertiary prevention efforts need to be more highly emphasized to complement the primary prevention efforts. This might also address the problem of staff motivation, where there is little feeling of making a difference when the focus is on primary prevention.

6. There needs to be more emphasis on reaching high risk groups. The program is well designed and supported for reaching the lower risk, target populations with primary prevention information. However, training bartenders, police and court officials and helping them set standards for referral are needed.

3. **PENNSYLVANIA PROJECT FOR PREVENTION OF FETAL ALCOHOL AND DRUG EFFECTS** (1982-1983)

REFERENCES:

Ronan, L. (1985). State Strategies for Prevention of Alcohol-Related Birth Defects. Alcohol and Health Research World, 10(1), 60-67.

TARGET:

- all women of childbearing age or younger, the general public, and helping professionals.

DESCRIPTION:

- the goals were:
  a) to encourage women of childbearing age to avoid alcohol and unnecessary drugs during pregnancy,
  b) to urge women with drinking problems to seek treatment,
  c) to influence health, social service and education professionals to provide education on alcohol and drug effects to all patients, clients and students prior to and during pregnancy, and
  d) to intervene with high risk women.
- further information unavailable

RATIONALE:

- comprehensive programs implemented at the community level are the most successful for educating prospective mothers
- this program takes a comprehensive approach in that there are many targets for intervention.

4. **FETAL ALCOHOL SYNDROME PREVENTION PROGRAM**

Lincoln Council on Alcoholism and Drugs, Inc.
914 L Street
Lincoln, Nebraska 68508
J.D. Creason, Executive Director
Jane Hentzen, Program Director
(402) 475-2694

REFERENCES:

Office of Substance Abuse Prevention. (1989). Twenty 1989 Exemplary Prevention Programs: Helping Communities to Help Themselves. Project Summaries.

Ronan, L. (1985). State Strategies for Prevention of Alcohol-Related Birth Defects. Alcohol Health and Research World, 10:(1), 60-67.

TARGET:

- targets women at high, moderate and low risk at each stage of maternal child health care continuum, i.e. preconception, prenatal, intrapartum and post-partum.
- services are also targeted to lay persons and health care professionals

DESCRIPTION:

- The ultimate aim is to decrease the number of new FAS/FAE cases and to create awareness that consumption of alcohol during pregnancy can have negative effects on the unborn baby.

- utilizes a prevention framework based on primary, secondary and tertiary prevention modalities for each stage of the maternal-child health care continuum.

- Primary prevention: targets low and moderate risk women

    - teacher training for junior and senior high teachers on the use of a FAS prevention curriculum
    - public information and education through mass media campaigns, Public Service Announcements, and distribution of written material to agencies and organizations that serve women.
    - professional education for health and human service workers
    - provision of updated information to nursing schools for use in curriculum development

- Secondary prevention:

    - professional training and consultation with health and human service workers on the identification of high risk women, and counselling

techniques
- development of a resource centre providing up-to-date materials and information for workers in the field.
- assistance with the development of screening and risk assessment tools.
- use of a screening questionnaire to evaluate alcohol and other drug use

- Tertiary Prevention:
  - providing referral information and guidance for professionals who have identified alcohol abusing women and affected children
  - referral assistance for families and individuals with affected children
  - support services and programs for women with FAS children
  - educational support groups provided to treatment centres and outpatient programs

- program began as a pilot project in 1984, but has since expanded its services which are based on and emphasize those activities which have proven to be most effective.

- the program has an Advisory Board with representation from a broad cross-section of community based agencies

EVALUATION:

- During 1987/88 the following was accomplished:
  - direct services provided to 142 clients
  - education and training services to 6,261 individuals
  - reached over 320,000 people through media campaigns and public displays
  - distributed 45,500 pieces of literature

- the program has a strong evaluation base, using both process and outcome evaluation techniques
- impact evaluation consists of pre-post testing of training participants which demonstrate consistent improvement
- evaluations by participants have been positive
- 7.7% of 981 program respondents were identified as being at risk, or having symptoms of alcohol abuse or dependence
- Received an award from the Department of Health and Human Services as one of Nebraska's Outstanding Health Promotion Programs
- Received the Prevention and Education Commendation Award from the National Council on Alcoholism.
- Cited as one of twenty exemplary prevention programs in 1989 by the Office of Substance Abuse Prevention.

5. **PREGNANCY AND HEALTH PROGRAM**

University of Washington
Department of Psychiatry and Behavioral Medicine
Department of Obstetrics and Gynaecology

REFERENCES:

Little, R. Streissguth, A. & Guzinski, G. (1980). Prevention of Fetal Alcohol Syndrome: A Model Program. Alcoholism: Clinical and Experimental Research, 4(2), 185-189.

Little, R., Streissguth, A., Guzinski, G., Uhl, C.N., Paulozzi, L., Mann, S.L., Young, A., Clarren, S., Grathwohl, H.L. (1985). An Evaluation of the Pregnancy and Health Program. Alcohol Health and Research World, 10(1), 44-59.

TARGET:

- General public
- Health professionals dealing with pregnant women, especially obstetricians, family practitioners, midwives, childbirth educators, and prenatal clinic staff
- Pregnant women who use alcohol during pregnancy

PHILOSOPHY:

- the problem of fetal alcohol syndrome is seen as a public health problem of major proportion, and thus a "public health approach" is taken.

- the underlying philosophy is that mothers, given a choice, will opt for health - thus, the emphasis is on health. This is reflected in the name, "Pregnancy and Health Program". All educational materials stress the importance of health, and clients are encouraged and supported to act in responsible ways to improve health. The atmosphere is relaxed and encourages "drop ins", which the program staff believes alleviates much of the fear and shame that accompanies a drinking problem.

DESCRIPTION:

- The primary goals of the program were to demonstrate effective ways of intervening in alcohol abuse during pregnancy, to minimize fetal damage in current pregnancies and to prevent it in future pregnancies.
- consists of five major program components:

1. Public Education

   - to increase public awareness of the dangers of drinking during pregnancy
   - aimed at pregnant women and women of childbearing age
   - primary method is media coverage: television, radio, newspaper
   - distribution of 70,000 brochures a year to places where women might

see them, such as diaper service deliveries, marriage licence bureaus, laboratories where pregnancy tests are done, prenatal clinics
- public speaking engagements to women's clubs, schools, PTAs, etc.
- all public information materials encourage self-referrals for help

2. Professional Training

- directed to professionals in all disciplines where the pregnant woman and/or the alcohol-affected child may be encountered.
- highest priority to persons providing prenatal care
- major goal is to encourage identification and referral of women and children who need program services
- format was continuing education workshops and inservice training
- a standard professional training package was developed that was adapted to the needs and interests of various professions
- training was provided by the program's professional multidisciplinary team (physicians, nurses, social workers, psychologists, and alcoholism counsellors). The trainer was the same discipline as the trainees.
- brochures for professionals describing program services and encouraging referrals
- results demonstrated increases in awareness of the risks of alcohol use during pregnancy and changes in referral patterns.

3. Telephone Hot Line

- 24 hour crises line which dispensed (over a 2 year period) information about alcohol effects during pregnancy and, when appropriate, made referrals
- staffed initially by trained volunteers but found paid professional staff to be more effective
- 4,306 calls total, 546 callers screened for alcohol use during pregnancy, 41% of those were risk level.
- Risk-level callers more likely to call in first trimester, to talk longer about concerns, and five times more likely to become PHP clients.

4. Screening and Counselling Services

- screening was conducted in a prenatal clinic to determine women at potential risk
- all those classified "at potential risk" were urged to make a counselling appointment
- follow-up contact was made with these women. Some received information and education at the follow-up call combined with on-going prenatal care. Others were strongly encouraged to attend in-person counselling.
- most at risk women who received counselling reduced their alcohol intake during pregnancy

5. Pregnancy Outcome Assessment

- an evaluation was done comparing pregnancy outcome of at risk women who became PHP clients with the outcome of women who reported no alcohol use during pregnancy.
- more favourable pregnancy outcomes were reported among at risk women who reduced alcohol than those who continued to drink

6. **TUBA CITY FAS PREVENTION PROGRAM**

U.S. Public Health Service Indian Hospital
Tuba City, Arizona 86045
Kathleen Masis, M.D., Program Director
(602)283-6211

TARGET:

- Pregnant women and their families in the Tuba City Service Unit of the U.S. Public Health Service Indian Hospital.
- Target population resides in the largest Indian reservation in the country, the Navajo.
- Widespread poverty with average per capita income of $2400 (1980 census).
- 5.9 of every 1000 women of childbearing age give birth to babies with FAS/FAE

DESCRIPTION:

- Participants are referred by the Indian Health Service, the Navajo Tribe, local service providers and criminal justice officials.
- Program services were based on a survey of FAS-related attitudes and educational needs of the community which found:
  a) there were no prevention activities available to the target population,
  b) screening for alcohol use by pregnant women was not being done, and
  c) no community education on FAS was in place.

- Services include:
  - individual services to high-risk women and mothers of FAS children, which include case management, assessment, education counselling, referral and support services.
  - intervention, education and counselling for participants' families, coordinated through the Navajo Division of Social Work Child Protective Service.
  - training of service providers from a variety of agencies.
  - community services, including presentations to community groups, casefinding, and development and support of a community board that will continue FAS prevention activities.

EVALUATION:

- limited evaluation data available at this time, but at the time of report (1989):
  - 181 professional staff had been trained
  - 66% of women entering treatment before 3rd month of pregnancy had stopped drinking
  - A screening mechanism had been implemented
  - An "FAS Awareness Month" had been held
  - the program was selected as one of twenty exemplary prevention programs by the Office for Substance Abuse Prevention, U.S. Department of Health and Human Services.

7. **FAS PUBLIC AWARENESS CAMPAIGN**

Manitoba Medical Association
Mr. Vic Taylor
Executive Assistant
(204)786-7565

TARGET:

- General population, urban and rural (including remote and isolated areas)
- English and French, currently negotiating to also produce in Cree

DESCRIPTION:

- program funded entirely from membership dues in the Manitoba Medical Association
- 30 second public service announcement on television during a 3 week period in early June, 1991.
- television companies have agreed to air two commercials for the price of one
- all local cable networks will be airing the television spot so that it will get into every remote community in the province.
- the purpose of the campaign is to increase the general level of public awareness about the dangers of drinking during pregnancy
- the 30 second spot is primarily visual and the basic message is that drinking while pregnant puts the baby at risk.
- the campaign slogan is "Fetal Alcohol Syndrome: the Preventable Birth Defect"
- at the same time, they are approaching bars, through the public health inspectors, asking hotels to voluntarily put up posters and signs in the bars.
- because they anticipate that many women may be motivated to approach their physicians because of the campaign, a physician information package is being prepared and will be distributed prior to the campaign
- in addition, a one-day paediatric update on substance abuse in pregnancy will be held for physicians

EVALUATION:

- prior to the campaign, a questionnaire will be sent out to a sample of physicians (rural and urban, GP and specialist) to determine their general level of awareness of FAS, and perceptions of their clients awareness
- in addition, 2000 women will be surveyed pre-campaign about alcohol use during pregnancy and levels of awareness re: FAS. The first 50 women who walk through the door of the sampled physicians offices will be asked to complete a questionnaire.
- post-campaign, physicians will again be surveyed as will an additional 2000 women to determine levels of awareness after the campaign

OUTCOME:

- following the campaign, if the evaluation indicates that the campaign was successful in increasing public awareness of FAS, they will make the 30 second video available to other medical associations across the country, with recommendations for implementation in other provinces.

APPENDIX C

CRITERIA FOR EFFECTIVE PREVENTION PROGRAMS

CRITERIA FOR EFFECTIVE PREVENTION PROGRAMS

The twelve important attributes of effective prevention programs are:

1. ***A Program Planning Process***: The program is based on a sound planning process. The planning process is conducted and/or affirmed by a group that is representative of the multiple systems in the community, such as family, church, school, business, law enforcement, judicial system, media, service organizations and health delivery systems, including alcohol/drug agencies involved in referral, treatment and aftercare.

2. ***Goals and Objectives***: The program has developed a written document that establishes specific, measurable goals and objectives that focus on alcohol and drug prevention. The goals and objectives should be based on a community needs assessment and reflect specific action plans appropriate to the target group.

3. ***Multiple Activities***: The prevention program involves the use of multiple activities to accomplish its goals and objectives. These may include information, education skills development for youth and adults; training of impactors, alternatives, environmental policy and public policy segments. The public policy segments may include the development of specific written school policies and/or local, provincial and national public policies on availability, marketing, and other relevant alcohol beverage control issues.

   The activities or strategies are implemented in sufficient quantity (no one shot deals) to have a positive effect on the targets. The program concept may have replicability for other communities.

4. ***Multiple Targets/Population***: The prevention program includes all elements of the community and/or population served, including all ages, such as the elderly, high-risk groups, and culturally specific groups. The impact and interrelatedness of each group upon the other must be recognized and emphasized in program development, i.e. youth usage is strongly influenced by community norms and adult role models.

5. ***Strong Evaluation Base***: The program has a mechanism for data collection on an ongoing basis and a method of cost analysis that can be used to calculate cost effectiveness. In addition, the outcomes of the evaluation need to include a focus on behaviour change and be tied back to the planning process so that appropriate programmatic changes can be made.

6. ***Sensitive to the Needs of All***: The program takes into account the unique special needs of the community/population. The community will not adopt, without study and adaptation, the package deals of another community, but will seek to redesign and tailor prevention programs to reach the specific needs of its own individuals and cultural groups, including different ethnic and gender specific efforts.

7. ***Part of Overall Health Promotion and Health Care System***: The prevention program is an integral, essential component of the health care system. It works with the other agencies that provide intervention, referral, treatment and aftercare components of the

continuum. It also seeks to work with other prevention agencies in order to build a supportive community environment for the development of healthy lifestyles and lifestyle choices.

8. ***Community Involvement and Ownership***: The prevention program reflects the basic, essential, philosophical understanding that prevention is a shared responsibility among national, provincial, and local levels and that specific programs are best done at community levels. "Grassroots" ownership and responsibility are the key elements in the planning, implementation and evaluation of the program. The prevention program should enable the community to not only examine its problems, but also take ownership and responsibility for its solutions.

9. ***Long-Term***: The prevention program recognizes that there is no such thing as a quick fix or bottled formula or a magic curriculum that will solve the problem. The prevention program seeks to promote a long-term commitment that is flexible and adaptable and responds to a changing environment. The prevention program seeks to build upon its successes and continually enhance its efforts toward its goal. The long term process integrates prevention activities into existing organizations and institutions such as families, schools, and communities. The long-term nature of the program ensures that interventions begin early and continue through the life cycle.

10. ***Multiple Systems/Levels***: The prevention program utilizes social systems and levels within the community in a collaborative effort. In order to impact a full range of target populations, all the social systems that are involved must be included (e.g. family, church, community youth recreation, the law enforcement system, etc.).

11. ***Marketing/Promotion***: The prevention program needs to include a marketing approach that showcases the positive effects that prevention has within the community and the effects it has on the various individuals and systems within the community. Policymakers are key targets for the marketing strategy. (For example, in marketing youth prevention programs, the involvement of policymakers in the marketing strategy may ensure the continuation of that prevention program.) Mechanisms by which programs can achieve self-sufficiency should be built into the design.

12. ***Replicability***: The prevention program has documented its philosophy, theory, methods, and procedures in sufficient detail and clarity to permit other organizations to assess its utility and applicability in their setting and to permit orderly development of a similar or related program in a new and (somewhat) different setting.

National Association of State Alcohol and Drug Abuse Directors, The National Prevention Network, and the Office for Substance Abuse Prevention. (1989) Helping Communities to Help Themselves: Twenty 1989 Exemplary Prevention Programs - Project Summaries, March.

APPENDIX D

NATIVE HEALTH CARE WORKER SURVEY

HEALTH WORKER SURVEY METHODS

A semi-structured telephone interview was conducted. A copy of the survey instrument is included in this Appendix. A telephone interview was determined to be the format most likely to achieve a high response rate at a low cost. Other recent surveys of the same population have had relatively low response rates (e.g. Friendship Centre Survey, 33%). Furthermore, the telephone format seemed most appropriate for the desired qualitative focus because it allowed for in depth probing of responses.

Pregnancy Outreach Program Coordinators (N=8), Drug and Alcohol Counsellors at Friendship Centres (N=21) and Community Health Representatives (CHR's) from randomly selected Native reserves (N=160) comprised the sampling frame. A proportional stratified random sampling procedure was utilized to select 30 CHRs.

All 8 POP coordinators were contacted and responded. Alcohol and Drug Counsellors in Friendship Centres where a POP program was located were not contacted because the information was likely to be duplicated. Thus only 16 Alcohol and Drug Counsellors were contacted and 15 responded. One respondent was unable to participate because of other demands.

The response rate for CHR's was very low because groups of CHRs are away from their communities for training at any one time. Thus, the final sample of CHR's (N=31) was not randomly selected, but rather was comprised of the only 31 CHR's we were able to contact during the time of the survey.

The focus of the interview was on the respondent's perceptions regarding the extent of FAS, the types of educational processes that work best with their clients, and levels of smoking and other drug use in the community. Respondents were also asked what FAS prevention activities they conducted, what they believed should be included in a comprehensive prevention program and what educational resources they would find helpful in their work.

There are several limitations to this survey. First, the survey was geared toward determining respondents *perceptions*. This may not necessarily reflect actual conditions in the community. In some cases, the person contacted may not have been the best person to respond to the survey. Finally, the sample size is small and non-random, therefore may not be representative. However, there is much consistency in many of the responses across groups, and the results are consistent with those of other assessments and surveys.

FAS NEEDS ASSESSMENT INTERVIEW SCHEDULE

1. Name of Respondent

   _____

2. Address

   _____

   _____

   _____

3. What is average educational level of your clients?

4. Do you believe that FAS is a problem in your community?

   _____ Yes _____ No Please explain

   _____

   _____

   _____

5. If the government was to fund a comprehensive FAS prevention program for the Native community in B.C., what do you think it should include? (If the individual focuses on the individual as the target, prompt for information on what a program targeting the community would include, and vice versa).

   _____

   _____

   _____

   _____

   _____

   _____

   _____

   _____

6. What kinds of educational processes work best with Native women in your community?

_____

_____

_____

7. Do you do any education regarding FAS prevention with your clients?

_____ Yes _____ No

What do you do?

_____

_____

_____

_____

_____

_____

8. What kind of education materials (for your clients) would help you in your efforts to prevent FAS?

_____

_____

_____

9. Is cigarette smoking during pregnancy common among women in your community?

_____ Yes _____ No (Probe for elaboration)

_____

_____

_____

10. Is the use of cocaine during pregnancy common among women in your community?

____ Yes _____ No (Probe for elaboration)

_____

_____

_____

11. Is the use of other drugs during pregnancy common among women in your community?

____ Yes _____ No (what other drugs?)

_____

_____

_____

12. Other Comments:

_____

_____

_____

_____

_____

_____

_____

_____

_____

RESULTS OF HEALTH WORKER NEEDS ASSESSMENT SURVEY

1.0 PREGNANCY OUTREACH PROGRAM COORDINATORS

1.1 Is FAS a Problem in the Community?

Fifty percent or more of the clientele in 6 programs were Native. Less than 10 percent of the clientele in the other 2 programs were Native. Six of the eight coordinators believe FAS to be concern in the community served by their program. One did not know and the other said that the problem of FAS was the same in her community as in the rest of the province.

1.2 Do You Do FAS Prevention Education?

All eight programs do some FAS prevention education. Education efforts in four programs consisted of one-to-one counselling and the T-ACE assessment[1]. Coordinators of four programs stated that they did not focus on FAS because their clients were unwilling to discuss the issue on a personal level. Some stated, however, that they may introduce the topic in a subtle way. Two programs have conducted FAS workshops or put up posters to increase awareness of FAS. The last two communities have conducted more extensive prevention efforts by involving the media and various segments of the community. Some of the activies were:

- a luncheon with community leaders to brainstorm on what could be done about FAS in their community.
- developed a booklet on FAS for pregnant women with redeemable coupons and "low-key" information about drinking during pregnancy
- sticker campaign for mirrors in bars with the logo (developed through focus testing) "Pregnancy: An Alcohol and Drug Free Zone"
- educating staff in licenced facilities about FAS and provided them with recipes for non-alcoholic beverages
- phone in program on local cable network
- invited speakers from FAS Resource Group to speak to health professionals in the community
- articles about FAS in a low-literacy publication

In summary, 75% of respondent's contacted perceived FAS to be an issue of concern in their community and although all programs did some work regarding FAS prevention education, only twenty-five percent actively maintained ongoing focused prevention efforts.

---

[1]T-ACE is a measurement tool which asks four questions which are significant predictors of risk drinking (Sokol, 1988).

1.3 Most Effective Means of Education

One-to-one counselling, group therapy, and testimonial videos were thought to be the three most effective means of education. Group work was effective only if trust with the facilitor was established.

Some suggestions for helpful resources included:

- resources (pamphlets) geared toward low-literacy groups,
- a variety of posters aimed at women in different categories (single, married, divorced etc.) so that more women would be able to identify with the issue
- Visual information
- videos that are fast moving and targeted to individuals with a short attention span
- A range of promotional materials such as magnets, mugs, t-shirts and posters with education messages

1.4 Substance Use During Pregnancy

1.4.1 Cigarette Smoking

Cigarette smoking during pregnancy was perceived to be common in the majority of the communities. Many women either cut back or quit smoking once they realize they are pregnant. This perception has been confirmed in the recent POP evaluation.

1.4.2 Cocaine Use

Cocaine use was not perceived to be a problem. Many respondents maintained that it was more of a concern in the non Native population than in the native population. Coordinators also stated that if it was common, they were unaware of it.

1.4.3 Other Substance Use

Use of other substances, however, was perceived to be a common concern. Eighty-seven percent of the respondents felt that use of other drugs such as marijuana, caffeine and hashish during pregnancy was common. Marijuana was stated to be a concern by eight-five percent of the respondents who felt other drug use during pregnancy was common.

1.5 Recommendations For a Comprehensive FAS Education Package

Several consistent recommendations for a comprehensive FAS prevention program emerged from the interviewing process:

- Many respondents felt FAS education should be conducted in the school environment at the high school level or earlier
- Pregnant women seem to be aware that alcohol consumption during pregnancy can be harmful to the fetus but are not aware of the extent of the potential damage, i.e. they need to be made aware of the long-term consequences

- Most respondents believe the literacy level of the available pamphlets are too high for their clients
- materials need to be more visual

Other comments included:

- There was a need to raise physicians' awareness of issues related to FAS and the need for early diagnosis
- Tertiary prevention efforts need to be increased: there is not enough support for caregivers of FAS children or for people who have FAS
- Secure funding for the program was a priority; the lack of this precludes long-term program planning and development
- Definitive information regarding risks associated with various levels of drinking is needed. When the information is vague or non-specific, a low compliance rate results
- There is a need to establish peer support programs because of a potential lack of trust in health professionals by at risk groups.

2.0 FRIENDSHIP CENTRES

2.1 Is Fas a Problem in the Community?

Thirteen of the fifteen respondents felt that FAS was a priority health issue in their community. One respondent stated that pregnant women were not part of his clientele and did not feel confident in answering the question. One respondent felt that it was no longer a big problem in his community.

Many respondents felt that although a diagnosis of FAS had not been made in many individuals, they exibited signs and symptoms of the condition.

2.2 Most Effective Means of Education

Eight respondents stated small groups or support groups were most effective. Six people stated one-to-one counselling was also an effective method of communicating FAS prevention messages. Four respondents stated that videos were an effective means of health education for their clients.

2.3 Do You Do FAS Prevention Education?

Six alcohol and drug counsellors stated that they did no FAS prevention education with their clients. Reasons for this included:

- they were not up to date on the issues,
- they dealt mainly with FAS clients themselves
- efforts were in the process of being initiated

One respondent stated that occasionally one to one counseling for FAS was conducted.

Seven counsellors said they did do FAS prevention education on a regular basis with their clients. This consisted of either: one-to-one counseling, small group sessions, putting up posters during drug awareness week, or conducting workshops.

2.4 Resources That Would Be Of Use

Many of those contacted felt that the resources that were available for FAS prevention were not appropriate. Problems with these resources included:

- they were not culturally appropriate
- the literacy level was too high
- materials were too wordy and not visual enough
- resources were not "local" in that they weren't specific to that community.

Suggestions were made to have:

- native specific resources
- information that was appropriate for a grade seven or eight reading level
- material should be more visual with less words
- funding for the same facilitator to conduct workshops on an ongoing basis so that trust could be established and maintained.

2.5 Substance Abuse During Pregnancy

2.5.1 Cigarette Smoking

Thirteen of the fifteen counsellors perceived cigarette smoking to be common among the Native population in their community. However, four counsellors felt that it was no more common among the Native population in their community than in the general population. One respondent felt that although cigarette smoking was common in the community, women either quit smoking or cut back on the amount smoked once they realized they were pregnant.

2.5.2 Cocaine Use

Six respondents did not perceive cocaine use to be common among the pregnant women in their community. Reasons given for this included:

a) Counsellors either were unaware of cocaine use due to lack of reporting, or
b) cocaine use was more common among people with a higher level of income than the clients served by their centre.

Seven respondents didn't know if cocaine was commonly used in their community.

Two counsellors stated that it was common because there were cocaine addicted babies born in their community.

2.5.6 Other Substance Use

Thirteen drug and alcohol counsellors reported that other drug use was common during pregnancy. Substances most commonly used included marijuana, caffeine, anti-depressants and over-the-counter drugs.

The two remaining counsellors stated they did not know whether drug use was common during pregnancy.

2.5.7 Recommendations For a Comprehensive FAS Prevention Package

Respondents felt the following components should be included in a comprehensive FAS prevention education program:

- education efforts should be initiated at a high school level or earlier
- it was important to communicate the impact that FAS has on a child and the family; women may seem to be aware that drinking during pregnancy can harm their baby but are unaware of the magnitude of the impact and its lasting effects
- FAS education should be part of a more comprehensive approach which includes information on: nutrition, the roots and causes of Native oppression, that alcohol is a symptom of a larger problem not the actual problem itself, self-assertion skills, self-empowerment, etc.
- a "train the trainer" hands on type of approach in which credible and trusted local women are trained to disseminate information on a one to one basis throughout the community (on reserve)
- material would be more effectively communicated if it was presented by Natives
- alcohol was not the only harmful substance to a fetus, but that other "innocuous" drugs such as Tylenol were also detrimental to a fetus

3.0 COMMUNITY HEALTH REPRESENTATIVES

3.1 Is Fas a Problem in Community?

Approximately half of the CHRs (16/31) believe that FAS is a problem in their communities. Of those that answered no, some stated that FAS used to be a problem but was no longer an issue, while others felt that FAS was a problem for other communities. One person stated that although FAS was not a problem in that community, but that of the women who do drink during pregnancy, 1 in 5 are heavy drinkers and the rest are moderate drinkers.

3.2 Most Effective Means of Education

One-to-one counselling (N=17) and videos (N=11) were suggested as the two most effective means of education. Workshops (N=4) and support groups (N=4) were also mentioned. Group counselling and testimonials were mentioned by only one or two CHRs. Other comments made included the importance of using a variety of methods to encompass different ways of learning. One-to-one counselling is often the only method used because of lack of resources. Home visits may also be an effective method.

3.3 Do You Do FAS Prevention Education?

Only 8 of the 31 CHRs responded yes to this question. Eighteen said they do not do any FAS education, while 5 responded "sort of" or "once in a while". Education efforts consist primarily of one-to-one counselling, handing out information pamphlets and posters, and talking about FAS to women who were in prenatal sessions (these women were perceived as being at low risk). Occasionally videotapes are presented.

Some of the CHRs did not believe the at risk population was being reached. FAS prevention efforts appeared to be directed at those who are at low risk.

3.4 Resources That Would Be Of Use

Of the 31 CHRs, 17 stated that videos would be the most helpful resources to have. Nine stated that literature and pamphlets would be helpful. The materials should be culturally appropriate. Four respondents suggested that they need "educated people who know about FAS". Many CHRs were unaware of Medical Services Branch resources or how to access FAS materials. Those that knew felt that the materials were inaccessible and there were long waiting lists for videos from MSB in Vancouver. In general, the CHRs were anxious to obtain any information on FAS. Other suggestions included the developement of a teaching package on FAS, which would include materials that mothers can take home.

3.5 Substance Abuse During Pregnancy

3.5.1 Cigarette Smoking

Thirteen CHRs responded that smoking was common among pregnant women in their community. Nine stated that some women smoked during pregnancy but most will quit when they discover they are pregnant. Five respondents said no, that smoking was not common during pregnancy and four did not know. One respondent stated that many women chew tobacco.

3.5.2 Cocaine Use

Twenty-two CHRs stated that the use of cocaine was not common in their communities. Four stated that they did not know. Five made other comments such as, there may be some use but it is hidden, it may occur occasionally, there are cycles of high use alternating with low use, or that it is common among the men but they did not know about pregnant women.

3.5.3 Other Substance Use

Marijuana use was declared to be common by 9 of the respondents. Five suggested that coffee was used commonly during pregnancy. Two stated that prescription drug use during pregnancy was a problem. Five respondents said they did not know and 10 answered no, that the use of other drugs was not common.

3.6 Recommendations For a Comprehensive FAS Prevention Program

Nine respondents did not know what should be included in a comprehensive prevention program. Eight stated that education in the schools at an early age was important. Only one suggested a public awareness campaign. Ten suggested resources which included either pamphlets and posters, eye catching visual information, or videos. One person suggested legislation. There was a general feeling that Native people should be consulted in the development and that a Native "approach" should be used.

Other suggestions included the development of an information package for young mothers and pregnant teens. The problem of accessing mothers early enough in pregnancy was raised as a concern. Elders could be utilized effectively to teach their grandchildren, because they are respected members of the community and can get the message across. Resources are needed right on the reserve, especially in isolated communities. Another suggestion was that training of Native people in workshops so that they can come back to the community with the information.

APPENDIX E

REVIEW OF FETAL SYNDROMES PREVENTION EDUCATION PRINT MATERIALS

1. **FAS RESOURCE KIT** (1988)

Saskatchewan Institute on Prevention of Handicaps
Box 81, University Hospital
Saskatoon, Saskatchewan
(306) 966-2512

Target: Resource personnel with medical/health background

Description: Attractive paper folder containing printed material, bearing logo of the Agency.

Booklet: What everyone should know about Fetal Alcohol Effects.

Target: High school students
General public

Strengths: Covers both FAS and FAE.
Language is simple, easy-to-read.
About Grade 6 reading level.
Emphasizes that there is a spectrum of effects.
Points out that some of the symptoms may be caused by factors other than alcohol use, thus reducing potential for blaming and inducing guilt.
Can be purchased in bulk and apply local agency/Government sponsorship label, thus making the information locally relevant.

Weaknesses: Literacy level may still be too high for some at-risk populations.
Fairly lengthy (15 pages) thus may be inappropriate for some groups.
Some of the technical information may be confusing.
Emphasis on "no safe amount" may be misleading.
Information may be a bit vague.

Poster: Baby care begins before birth.

Target: General public

Strengths: Generic message recommending prenatal care by a physician

Weaknesses: Message is vague and non-specific, does not mention FAS or alcohol/drug use during pregnancy.
It provides no information about prevention of FAS, or concrete suggestions for things mother/parents can do to prevent FAS

Fact Sheet: Prevention Facts

Target: General public

Strengths: Short, easy to read. Probably about Grade 6-7 reading level.
Easy to reproduce on coloured paper
Emphasizes no known safe limit of alcohol consumption
Good Message/Logo: A Pregnant Woman Never Drinks Alone

Weaknesses: Saskatchewan specific
Incomplete information
Illustration doesn't fit with description, i.e. demonstrates only one of the FAS criteria
Not professionally done .
Too wordy for very low literacy women.

Letter of Introduction: includes an evaluation form

Articles:

Saskatchewan data:
1) Nanson, J. (1981) The Saskatchewan Scene.
2) Zaleski, W.A. (1984) FAS

Epidemiology and Etiology:
1) Iber, F.L. (1980) Fetal Alcohol Syndrome.
2) Smith, D.W. (1982) FAS and FAE.
3) Ives, E.J. (1987) The FAS.
4) Enloe, C.F. ( ) How Alcohol Affects the Developing Fetus.
5) Streissguth, A. (1985) A Natural History of FAS.

Psychological and Behavioural Effects:
1) Streissguth, A. & LaDue, R.A. Psychological and Behavioural Effects on Children Prenatally Exposed to Alcohol.

Management of Children with FAS/FAE:
1) Zaleski, W.A. (1982)
2) Rogan, A. (1985) Issues in the Early Identification, Assessment and Management of Children with FAE.

Prevention:
Funkhauser, J.E. & Denniston, R.W. Preventing Alcohol Related Birth Defects.

All articles are fairly up to date, aimed at providing resource personnel with a broad perspective as well as some information on advice and counselling for women. There is limited information provided on Prevention.

FAS Resource List: written and audiovisual material.

Overall:

Strengths: Convenient, easily accessible information for health professionals. Provides copies of good, up to date reference articles by leading experts, so busy professionals do not have to track down information themselves.
Provides some information on advice/counselling to women in a one-to-one situation re: alcohol use during pregnancy.

Weaknesses: Limited focus on prevention. Prevention information is limited to advice-giving and appropriate messages for pregnant clients.
Provides no information on community strategies, networking, referrals, etc.
Focused on one-to-one intervention.
Much of the information is Saskatchewan specific.

2. **DRUG ABUSE AND PREGNANCY KIT** (1988)

Saskatchewan Institute on Prevention of Handicaps
Box 81, University Hospital
Saskatoon, Saskatchewan
(306) 966-2512

Target: Resource personnel with medical/health background

Description: Attractive paper folder containing printed material, bearing logo of the Agency.

Pamphlet: Drugs & Pregnancy: It's Not Worth the Risk

Target: Pregnant women
General Public

Strengths: Discusses most common addictive substances and their effect on the baby. States that cessation at any point in the pregnancy or even after is beneficial. Lists agencies and organizations that one can access for more information or help. Briefly discusses over-the-counter drugs and prescription medication.
Can be purchased in bulk and apply local agency/Government sponsorship label, thus making the information locally relevant.

Weaknesses: Heavy emphasis on consulting doctors instead other health care professionals.
Some information is a bit vague.
Lot of information and may discourage some groups.
Some technical language which may not be understood by some groups.
Toll-free number listed on back of pamphlet is not valid in British Columbia (probably Canada).
Some individuals may not identify with the use of some words such as "addict" or "heavy users" and may not take in the information.

Pamphlet: Having Problems with Alcohol or Other Drug Abuse? We'd Like to Help.

Target: Persons with, or knowing persons with, drug abuse problems

Strengths: Language is simple and easy to read

Weaknesses: Stresses the role of the family and spouse; may be a deterrent for persons without a support network.
Saskatchewan specific

Pamphlet: Alcohol and Other Drug Use in Pregnancy: Preventive Guide for Parents

Target: Expectant Parents

Strengths: Discusses both the role of the mother and the father.
Language is generally simple and easy to read.
Lists sources that can be of assistance.

Weaknesses: Some crucial sections are difficult to read.
Doesn't address the issue of stopping use of drugs at any time throughout pregnancy.
Saskatchewan agencies listed on publication.

One Page Flyer: Guess Who Else Can Get AIDS if You Shoot Drugs. Your Baby Can.

Target: General Public

Strengths:

Weaknesses: Large print vague; doesn't say anything about sharing needles and may be misinterpreted.
Suggests the use of condoms until getting an AIDS test to protect oneself; misleading.
Too many messages not communicated well; may lead to confusion and misinterpretation.

Fact Sheet: Drug Abuse and Pregnancy: Prevention Facts.

Target: General Public

Strengths: Language is simple and easy to read.
Would be simple to re-do with the name and address of local agency to contact for more information or help.

Weaknesses: Has a paternalistic tone.

Information Sheet: Congenital Aids

Target: General Public

Strengths: Information is divided into various sections according to common concerns.
Can be obtained in bulk from local March of Dimes chapters

Weaknesses: Some information may be misinterpreted and is not completely up to date.
Language in some parts is difficult to read and may not be understood by all groups.

Poster: Pregnant? Say "No" to Drugs!

Target: General Public

Strenghts: Message is simple and clear.

Weaknesses: Has address and logo Saskatchewan agency on poster which would need to be removed to make it locally relevant.

Fold-Out Chart: Drug Reference Chart

Target: Resource personnel with medical/health background.

Strengths: Contains information about a comprehensive list of addictive substances
Can be obtained in bulk and apply local agency/Government sponsorship label, thus making the information locally relevant.

Weaknesses: May be used as primary source of information by some health care workers
Doesn't include information on how to manage situations where these substances are being misused by clients.

Bookmark: Prevention is everybody's business

Target: Resource personnel (to whom kit is distributed)

Strengths: None

Weaknesses: Contains name and address of Saskatchewan agency
Not very useful

List of Materials on Drug Abuse and Pregnancy Available From Agency: includes a brief description of each item.

Order form to obtain materials on Drug Abuse and Pregnancy.

Summary of Articles sheet: presents a brief summary of each article included in kit.

Letter of Introduction: includes an evaluation form.

Articles:

1) Keith,L. et al. (1988) Drug Abuse in Pregnancy.
2) Schneider,L. (1986) The Pregnant Adolescent and Drugs.
3) Bingol,N. (1987) Cocaine and Birth Defects.
4) Fried,P. et al. (1984) Marijuana Use During Pregnancy and Decreased Length of Gestation.
5) Marion,R. et al. (1986) Human T-Cell Lymphotropic Virus Type III (HTLV-III) Embryopathy.
6) Hersh,J. et al. (1985) Toluene Embryopathy.
7) MacGregor,S. et al. (1987) Cocaine Use During Pregnancy: Adverse Perinatal Outcome.

Articles provide information on the effects of various on the fetus. Limited information on prevention or counselling pregnant women using addictive substances.

Overall: Useful information provided in convenient concise fashion.

Strengths: Lots of relevent information in easily accessible, easily understandable format. Much of the information can be either modified or stamped with local agency to make it relevant to specific community.

Weaknesses: Limited focus on prevention or management. Much of information is Saskatchewan specific.

3. **SMOKING AND PREGNANCY KIT** (1988)

Saskatchewan Institute on Prevention of Handicaps
Box 81, University Hospital
Saskatoon, Saskatchewan
(306) 966-2512

Target: Resource personnel with medical/health background

Description: Attractive paper folder containing printed material bearing logo of the Agency

Pamphlet: Pregnant? That's Two Good Reasons to Quit Smoking

Target: Pregnant Women

Strenths: Language is simple and easy to read
Eyecatching pamphlet
Easy to follow information

Weaknesses: Paternalistic and patronizing in some sections
Saskatchwan Specific

Booklet: Should You Smoke During Pregnancy?

Target: Pregnant Women

Strengths: Language is simple and easy to understand
Separated into sections answering common questions
Provides technical information about physiological effects on fetus without being complicated or patronizing
Provides information on effects of smoking on the baby even after birth
Talks about the effects of second hand smoke
Includes brief section on responsibility of the father
Can be obtained in bulk and stamped to make it locally relevant
Provides a list of agencies to contact for further information

Weaknesses: Implies it is easy to quit smoking

Fact Sheet: Prevention Facts: Smoking-Pregnancy & Young Children

Target: Pregnant women and parents

Strengths: Language is simple, and easy to understand
Organized by answers to common concerns
Details effects of smoking during pregnancy
Lists options on ways to get help to quit smoking and encourages a non-smoking environment.

Weaknesses: Saskatchewan specific: would need to be altered to make it locally relevant

Information Sheet: Low Birthweight

Target: General Public

Strengths: Acknowledges the various causes for low-birthweight
Addresses prevention as well as treatment
Can be obtained in bulk and stamped with logo of local agency to make it locally relevant

Weaknesses:

Information Sheet: Everyone Wins

Target: General Public

Strengths:

Weaknesses: Information is not useful: vague and non-informative
Saskatchewan Specific

Poster: Pregnant? That's Two Good Reasons to Quit Smoking.

Target: General Public/Pregnant Women

Strengths: Colourful and eye-catching
Simple clear message

Weaknesses:

Booklet: Second-Hand Smoke

Target: General Public

Strengths: Explains components of second-hand smoke and its effects
Language is simple and easy to read
Can be obtained in bulk and stamped with to make it locally relevant

Weaknesses: Patronizing tone
Fear-inducing
Intimates that people have little control over their environment

Pamphlet: Can We Help?

Target: Resources personnel (to whom kit is distributed).
Provides information on The Saskatchewan Institute on Prevention of Handicaps.

Letter of Introduction: Includes an evaluation form

Articles:

1. Shaman,D. It Might Have Been a Beautiful Baby.
2. Feldman,P. (1985) Smoking and Health Pregnancy: Now Is the Time to Quit.
3. Shiono,P., Kelbanoff,M. & Rhodes,G.G. (1986) Smoking and Drinking During Pregnancy: Their Effects on Preterm Birth.
4. Rubin,D.H. et al. (1986) Effect of Passive Smoking on Birth-Weight.
5. Neiburg,P. et al. (1985) The Fetal Tobacco Syndrome.
6. Stewart,P.J. & Dunkley,G.C. (1985) Smoking and Health Care Patterns Among Pregnant Women.
7. Section on Allergy, Candain Pediatric Society. (1986) Secondhand Cigarette Smoke Worsens Symptoms in Children With Asthma.
8. Stjernfeldt, M. et al. (1986) Maternal Smoking During Pregnancy and Risk of Childhood Cancer.

Articles are somewhat out of date but generally still relevant. Covers the effects of both smoking and second hand smoke on the baby in utero and post natally. Limited information on how to counsel patients to quit smoking, or evaluation of available smoking cessation programs for client referral according to individual needs.

4. **FETAL ALCOHOL SYNDROME INSTRUCTIONAL KIT** (1979)
March of Dimes, Puget Sound Chapter.

Cynthia Shurtleff, Consultant
Clay Robets, Health Education Coordinator
Robert J. Marum, Superintendent
Educational Service District No. 121
Seattle, Washington

Description: Instructional kit on FAS education for Grades 7 to 12. Contains photoboards, films, books, transparencies, a teacher's guide, and leaflets for distribution to students (When you Drink, Your Unborn Baby Does Too).

The teacher's guide was the only program component available for review.

Goal: The overall goal is to help young people make responsible decisions regarding pre-parenting behaviour and the use of alcohol and other teratogens.

The Guide is divided into two sections:

1. Learning Activities

   Lesson Plans for 3 hours of instruction, designed to involve students in expressing feelings, making decisions, and understanding values and behaviour and also to gain basic information on FAS. The guide provides ideas for integrating the content into other subject areas and encourages teachers to develop their own ideas for integrating the material into other subjects.

2. Resource Supplement

   Contains the factual information about FAS upon which the learning activities are based.

Strengths: Generally good program focusing on decision making and values clarification. Utilizes active learning concepts and at the time of publication, likely reflected state of the art knowledge on this type of learning approach.
Suggestions for incorporation into other subject areas are good, but could be expanded to include incorporation in sexuality education class.

Weaknesses: Most appropriate for white, middle class students, but could be adapted to use similar concepts with minority youth, but with culturally appropriate examples.
Resource material is outdated.

Manual is not "user-friendly" and packaging could be more attractive.
If care is not exercised by teacher, could become "blaming". The material does not discuss the importance of "accepting differences", but the format lends itself well to the inclusion of this type of message. Recent developments in high-school curricula to enhance self-esteem, improve decision-making and clarify values could be incorporated to improve.

5. **FAS PUBLIC AWARENESS CAMPAIGN RESOURCE PACKAGE**. (1990)
Department of Mental Health, Mental Retardation and Substance Abuse Services
Richmond, Virginia, USA.
(804) 786-3921

Target: Community groups, community agencies, health and social care providers, - provision of information targeting general public for public awareness campaign.

Description: Yellow paper folder containing written material, pamphlets, booklets, and suggestions for activities during Fetal Alcohol Syndrome Awareness Week.

Letter of Introduction.
Resolution and declaration of awareness campaign by the Governor of Virginia.

Pamphlet: Double Trouble: Drugs, Alcohol, Tobacco Use During Pregnancy (1989)

Target:
Pregnant mothers
General public

Strengths:
Accurate information
Clear, straightforward and factual
Discusses other drug use including common over-the-counter medications, caffeine, smoking and prescription drugs.
Not blaming

Weaknesses:
Wordy, lots of information, no pictures
Not appropriate for low-literacy individuals
The use of the word "abuse" in the title may result in casual/occasional users ignoring the message.
No alternatives to alcohol/drug use are suggested
Little information on where to go for help, except physician - thus may not be appropriate for some at-risk groups who do not access physician services.

Booklet: My Baby--Strong and Healthy (1986)

Target:
Pregnant women (low to moderate risk)
General public

Strengths:
Discusses alcohol as a "drug"
Not blaming, very positive approach
Information on how alcohol affects the fetus, and realistic discussion of how much drinking is harmful (at low doses risks are probably small, but safest choice is not to drink) thus it is not misleading and guilt provoking.
Presents discussion on "Thoughts on drinking during pregnancy", which stimulates thinking and decision making

More in-depth than Double Trouble
Presents alternatives to use of alcohol for stress reduction
Gives information on where to go for help (U.S. specific)
Information is in the public domain, so reprinting for use in other locations is possible.

Weaknesses: Very wordy, lengthy (15 pp.) therefore not appropriate for low literacy women

Booklet: What everyone should know about Fetal Alcohol Effects (1983)
Target: Pregnant mothers
General public

For discussion, refer to Saskatchewan kit discussed above.

Booklet: About Pregnancy and Drugs (1988)
Target: Pregnant mothers
General public
Also appropriate for use with high school students

Strengths: Companion pamphlet to "What Everyone Should Know about FAE"
Positive, up-beat presentation - "Healthy Baby Starts with a Healthy Mother"
Discusses street drugs, over-the-counter and prescription drug use during pregnancy
Simple, clear, easy-to-understand language, good use of drawings,
Grade 5-6 literacy level, good layout/design, maintains interest
Message is that Quitting at any time during pregnancy can help the baby
Messages are appropriate, not blaming or condescending
Provides information on where to get help
Recommends seeing a "health care provider", not just a physician, so may be better for some at-risk groups who may not access physician services.

Weaknesses: A bit long (15 pp).

Pamphlet: 3 Words About Drinking while Pregnant: DON'T DO IT (1989)
Target: Pregnant mothers
General public

Strengths: none

Weaknesses: Negative, wordy, blaming approach
Paternalistic - don't do this, don't do that!

May turn-off women who are drinking

Pamphlet: I Want to Have a Healthy, Happy, Baby

Target: Low literacy women (4th grade reading level)
Low-income, minority women

Strengths: Good, positive picture on the front (healthy, happy mom and baby)
Grade 4 reading level
Provides camera-ready copy so community groups/agencies can produce the pamphlet for public distribution
Gives a toll-free hot line phone number for information

Weaknesses: While front cover picture is positive, message is paternalistic and negative
Emphasis is on what the woman should not do
The statements about what she should do relate to getting help from others vs what she can do for herself, thus the message is not empowering
Black mom and babe on cover of "low literacy" pamphlet could be perceived as stereotyping, however, since the target is low-income, minority women this is appropriate.

Suggested activities for FAS public awareness campaign (typed page).

Presents 14 ideas for community agencies and resource people to implement during the campaign. Some of these ideas are specific to the local area, but could be readily adapted.
The ideas are easy-to-implement and inexpensive for community groups

Fact Sheet: Virginia Incidence of FAS

Fact Sheet: Fetal Alcohol Syndrome
Small printing, wordy, difficult to read

Poster: A Pregnant Woman Never Drinks Alone
An 8 x 11 inch poster on posterboard - white background, black and purple printing
Messages: A Pregnant Women Never Drinks Alone
Caution: Drinking during pregnancy may cause birth defects

Strengths: Easy to post in public locations because of its size (folds to 8 1/2 by 11)
Ethnic background of woman in drawing is not clear - could be

white, Native, Spanish but not Black.

Fact sheet on warning labels on alcohol bottles
Provides information on the two warning labels now on all alcohol beverages purchased in the United States.

Bibliography
1) Alcohol Use during the Perinatal Period
2) Substance Abuse during the Perinatal Period

Good general reference list, but very little information on prevention

Resource list for information on Alcohol Related Birth Defects
Brochures, pamphlets, audiovisuals, posters books

Evaluation form

Overall:

Strengths: Good overall resource package for community agencies and health care providers. Some of the resources for public distribution are very good, with accessible, accurate, and empowering messages. Some of the resources, however, are not recommended (see above). While many of the suggestions for community awareness strategies are limited to the local area, most suggestions are good ones that could be adapted for use in other locations.
Involves community agencies, and the community in prevention efforts.
Recommend the pamphlets Double Trouble, My Baby - Strong and Healthy, and About Pregnancy and Drugs for their clear, positive, non-judgemental and accessible messages.

Weaknesses: Little focus on high-risk women.

6. **ALCOHOL AND THE UNBORN BABY EDUCATION KIT**
Government of Yukon Territories

Target: Pregnant mothers, either in one-on-one counselling sessions or prenatal classes.
Some components for general public.
Originally sent out to all health centres in the Yukon for use by PHN's, later orders of the kit came from across Canada from health centres, schools and social workers.

Description: Large, flat, cardboard box with 12 enlarged photo prints backed on thick cardboard, handouts, two manuals, pamphlets, and posters. One of the first teaching kits to be developed in Canada, originally as an aid to Public Health Nurses. The original kit came in a large briefcase.

Photo Prints: 12 large photo prints showing fetal development, the pregnant mother and developing fetus, and birth defects in children due to maternal drinking.

Leader Manual: Guide for preparing education programs.

Leader's Supplement: Contains background information on the effects of alcohol on the unborn baby and a bibliography for further study.

Pamphlet: For Baby's Sake Don't Drink

Target: Pregnant mothers
General Public
Low literacy

Weaknesses: Cartoon pictures with simplistic warning statements
Negative, "talk-down-to" presentation
Some misinformation
Vague

Strengths: Low literacy, accessible messages for some at-risk groups
Already in use in British Columbia

Poster: For Baby's Sake Don't Drink

Target: General public
Pregnant mothers

Soft, vague message
Pleasant imagery

Fact Sheets:

1. Facts About Alcohol
2. Pregnancy and Alcohol
3. How does the unborn baby develop?
4. Alternatives to Alcohol

Target: Pregnant mothers
General public

Plain, straightforward, factual information

Overall:

Strengths:

At one time was the only available kit in Canada.
Contains some good resource material.
Information for low-literacy, at risk groups.
Some good information for one-to-one education with pregnancy women in context of prenatal care.

Weaknesses:

Effectiveness is likely to be primarily dependent upon skill of person presenting the information.
No community-based, community-wide prevention strategies.
A rather unstimulating education program that does not reflect current research in prevention programming.
Limited scope - no information on dealing with pregnant women in terms of feelings, attitudes, values (particularly important in one-to-one interaction).
Could be "victim blaming" and guilt inducing depending upon the method of information presentation.
No information on appropriate format of advice/message to pregnant women, and no information on where to get further help/referral.

7. **WELL BABY KIT**. (1990)
Yukon Association for Community Living

Target: Pregnant women

Description: A canvas bag with the logo "Alcohol shatters the circle", containing a large T-Shirt with the same logo, several pamphlets, brochures and booklets on all aspects of pregnancy. Given out to all pregnant women.

Canvas Tote Bag Alcohol shatters the Circle (logo - message)
Cotton T-Shirt Alcohol shatters the Circle (logo - message)
Brochure on Fitness
Brochure on Nutrition
Booklet on Traditional native nutrition from the Council for Yukon Indians
Pamphlet: For Baby's Sake Don't Drink (described above)

Booklet: Johnson and Johnson's, Prenatal Diary

Pamphlet: March of Dimes, Preventing Birth Defects

Booklet: Johnson and Johnson's, Baby Care Basics.

Brochure: Kaushi's Place, Shelter for battered women
Pamphlet: Rating Your Prenatal Lifestyle

Brochure: Babies and Buckets (car seats)

Calling Card: Various community services for pregnant women and mothers of young children

Strengths: Attractive "goodie bag" with a wide variety of information for the expecting mother. This kit has been sent out to all health centres in the Yukon and is being given to all expecting mothers. It is still very new, thus there are no evaluation data.

Weaknesses: Limited scope of information. Much of the information is unrelated to FAS/FAE. The idea is good, but better material is available.
Many women do not get the package until well into pregnancy (i.e. third trimester).

8. **PROTECT OUR FUTURE GENERATIONS, PREVENT FETAL ALCOHOL SYNDROME**.(1988)
California Urban Indian Health Centre

Target: The kit itself targets Community resource people who serve the Native population, but much of the information can be given to the general public, pregnant women, high school students, etc.

Description: Large, flat, cardboard box containing a three ring binder, pamphlets, booklets, fact sheets, coasters, book marks, decals, photo, post cards, and poster.

Training Resource Manual:

Three ring binder containing:
Kit script
Resource Guide
Technique for approaching women at risk
Glossary of FAS terms
Bibliography

Target: Community resource people, both professional and lay workers

Strengths: Very well laid out. It assumes leader already has a working knowledge of FAS. The aim is at primary and secondary prevention.

Poster: An Inner Voice Tells You Not to Drink

Fact Sheets: Questions People Ask
Symptoms of FAS
Historical Perspectives
Related demographics

Target: General public
High School
Pregnant mothers

Strengths: Well presented and laid out on colourful thick sheets of paper
Factual
Credible, includes information sources and program address

Brochure: Warning Effects of FAS

Target: Native population
High school
Pregnant mothers
General Public

Abrupt and hard hitting
Deals with the most serious aspect of FAS - neurological impairment

Brochure: Should I Drink?

Target: Native population
Pregnant women

Strengths: Simple, clear message

Brochure: Guide for FAS Prevention

Target: Resource people working with Native population

Strengths: Short overview for resource people. It would probably be good for busy community leaders to quickly and better understand what the resource person is teaching and why.

Bookmarks: A Pregnant Woman Never Drinks Alone (message)

Recipe Book: Non-alcoholic drinks

Bumperstickers: Pregnancy and Alcohol Don't Mix (message)

Postcard: Message - An Invitation to Good Health

Fridge Magnet: No Risk Recipe - Healthy Baby Recipe

Decal: Prevent FAS

Photo: Young boy with FAS, summary of physical signs

Strengths: Diverse modes of information presentation. Clear, simple messages, but they tend to reflect traditional paternalistic approach to health education. The fact sheets are good: the colours, presentation, topics, information all seem to be effective and easy to read. The variety and flexibility is excellent. In a workshop setting, for example, the presenter could use as many or as few props as fit the situation. This is appropriate for the wide range of knowledge and skills present in community resource people. All the material is aimed at the Native American population, with no emphasis on the fact that FAS/FAE affects all racial groups. It would be easy to conclude that this is an "Indian Problem".

"Cadillac" version of a resource kit. Diverse modes of information presentation are used with simple, clear messages. The messages tend to be paternalistic. It assumes no knowledge or exposure to FAS/FAE of clients in real life, and therefore does not deal with the feelings and attitudes of an at-risk population.

9. **YOUR CHILD, OUR FUTURE - FAS EDUCATION PACKAGE AND RESOURCE KIT.**
Oromocto Indian Nation and NAADAP

Description: Large, white, attractive looking binder containing typed pages. Includes an introduction and seven sections separated by tabs. The kit was updated and published in 1989.

Target: Native service providers (drug and alcohol workers, educators, health workers, child and family service workers, etc.) in Native communities.

Introduction: Describes how to use the education binder. It states the purpose and lays out the two major segments: education and resources.

Section 1: **What do we know about FAS/FAE?**
History of FAS, epidemiology and etiology
Characteristics of the syndrome and effects.

Strengths: Good, well researched, up to date background information
Based on the results of recent North American studies.
Well written and readable for those with higher levels of education.

Weaknesses: May be written in a way that is over the heads of some community resource people.
Information on prevention is limited. No information on the "how to" of developing and implementing effective prevention strategies in Native Communities. The recent prevention literature is not reflected here.
Very "dry" presentation - not "user friendly".
Reorganization of the material with summaries, bullet points and ideas for community interventions (in Native communities) would improve the section.

Section 2: **Frameworking in a Prevention Context.**

The assumption of this section is that information alone will not prevent FAS; what is needed is a review of Spiritual and Traditional ways. It offers a process to facilitate a review of "our responsibilities as individuals and as a people by looking at how we feel and behave, with respect for ourselves, at home, at work, and in the community".

Strengths: Reflects an understanding of the importance of Native spiritual and traditional cultural values in prevention efforts. Recent research demonstrates that effective prevention in ethnic communities involves utilizing and basing programs on traditional values and culture.

Weaknesses: There is only a vague theoretical link between the process suggested and the desired outcome. The process requires that participants come to terms (on the spot) with their own spirituality, in the way that is set out in the exercise. This may be perceived by some as "preachy" and

"paternalistic".
The process requires a very skilled facilitator who understands the roots of cultural oppression, is familiar with spiritual development and has experience in conducting this type of workshop.
This may be an unrealistic expectation of the vast majority of community resource people who access this manual.

Section 3: **Presentations on FAS and FAE?**

Step-by-Step preparation is described for educational workshops aimed at:

1. the general public
2. junior and senior high school students
3. pregnant women and women of childbearing age, and
4. professionals and paraprofessionals.

Each presentation outlines activities, educational objectives for that particular group, then scripts the information content. The preparation activities vary, but the information content remains the same for all but the professional and paraprofessional groups.

Strengths: Good format for group presentation.
Very helpful for presenters to have step-by-step preparation and the background information is generally good.

Weaknesses: Assumes that group presentations are the most effective way to effect change in communities. This is the only prevention strategy presented in the manual.

The purpose of the presentations is to change behaviour through increased awareness. While increased awareness is clearly an important component of prevention, it is not sufficient for behaviour change. The socio-economic and political realities of Native communities must be considered in any prevention strategy and a broader range of strategies would be very useful.

There is a danger of blaming and guilt induction. It is likely that in a community presentation of this type, there may be individuals present who have direct experience with FAS or who drank heavily during pregnancy. The manual does not discuss how to handle the issues that may be raised in the presentation - i.e. guilt, acceptance of those affected/responsible.

The story in the lecture is simplistic and crude. While it is likely to make the desired point, it could be perceived as "blaming". There is a risk of losing some of the audience, particularly those "at-risk".

Section 4: **Annotated Bibliography with Author and Subject Index**

Lists 172 annotated journal articles, 19 audiovisual resources, and 24 books related to FAS/FAE.

Strengths: Good cross-section of articles.
Comprehensive list of AV resources, brochures, pamphlets, etc.

Weaknesses: The length of the bibliography is formidable.
An organization of the list by topic would have been helpful.
The information on prevention is limited. Access to libraries to obtain the original article is also limited in most rural communities, so most of the information in the bibliography is not accessible. It might have been useful to include copies of a few of the most relevant articles.

There is no prioritization or evaluation of the articles or resources.
Some of the resources are overtly racist (e.g. Videotape "Born Drunk") and clearly inappropriate for use in Native communities.
The addresses provided for the AV resources are "purchase" addresses. There is no information provided on where resources can be borrowed (e.g. Medical Services Branch Library).

The resource list will quickly outdate. It would be helpful to build in some mechanism for regular updates.

Section 5: **Glossary of Terms**

Terms relating to FAS and FAE found in this kit are defined in plain, easy to understand language. It is clear and straightforward. Some of the terms, however, seem inappropriate and unnecessary to include.

Section 6: **Self-Administered FAS/FAE Awareness Questionnaire**

15 true or false questions on different aspects of FAS/FAE, with an additional 5 questions for women only. There is a second set of true and false questions worded in a simpler way. The answers and an explanation for each question accompany both sets. The purpose of the questionnaires is for evaluation (pre and post tests). There is no indication of reliability and validity of the instruments.

Some of the questions could be misleading and misinterpreted. It would be necessary for a leader to clarify some of the ambiguity.

Section 7: **Common Questions and Reliable Answers on FAS**

A thorough list of questions on several aspects of FAS/FAE with detailed answers and a bibliography for each is included.

Strengths: A fairly comprehensive list of most possible questions, and for the most part, the answers are accurate. However, with respect to "prevention", the only answer provided is that "to prevent FAS a woman should not drink during pregnancy". There is very little information on how this can be accomplished or what help is available. There is no information on any other prevention approaches that could be implemented on a community level.

Overall: The content for the overview section is accurate and up-to-date, but would benefit from some "repackaging".

The prevention approaches are limited in scope and are based on studies that did not examine prevention strategies within Native communities. The complex nature of FAS requires a complex approach to prevention. This manual presents a limited scope of prevention activity.

The educational presentations assume the workshop participants have a "clean slate" with regard to any personal involvement with FAS/FAE. They do not deal with handling feelings and attitudes such as guilt, shame or anger which may be expressed or felt by participants.

The workshops do not place the problem of FAS/FAE in a socio-economic and political context such that the information and strategies presented may not "fit" the people and the community. In other words, they do not start where the people are "at".

In summary, the kit offers some good information that is not otherwise accessible to community resource people. However, much of the information may be inappropriate for some groups and individuals. The entire package would benefit from a "repackaging" of the material into a "user friendly" format and an expansion of the strategies for community based prevention.

We would not recommend the package be used in Native communities as is.

APPENDIX E

REVIEW OF FAS AUDIOVISUAL RESOURCES

REVIEW OF FAS VIDEOS

Fifteen videos were reviewed and evaluated according to the following criteria:

1. Content and focus of presentation.
2. Is the material up to date and accurate?
3. Is the material presented in an appealing manner?
4. What audience would the film be most appropriate for?
5. Strengths and Weaknesses?
6. Overall rating (poor, fair, good or very good)?

The films and videos reviewed here were those that were accessible to the review team, and thus accessible to Community resource people in Native communities. The list is not comprehensive but the cost of rental and purchase of additional videotapes precluded their inclusion in the review. The reader is referred to the NNADAP resource, Your Child, Our Future! for a more extensive listing of FAS audiovisual resources.

The source of the videos reviewed was the Medical Services Branch Audiovisual Resource Centre, and Sunnyhill Library. Inquiries were made at both the Ministry of Health and Alcohol and Drug libraries but there were only one or two films on the subject of FAS/FAE. The most comprehensive source was the MSB Audiovisual Resource Centre.

Note 1: Fifteen films were reviewed. Two of the films which were listed as an FAS AV resource in the MSB Resource Centre were actually not about FAS. **Soft is the Heart of a Child** deals with children growing up in a home with alcoholic parents. It does not mention FAS or FAE. **A Weigh of Life**, deals with obesity, not FAS. We recommend that these two films be removed from the FAS listing.

Note 2: In reviewing the films and videos, we inquired about the frequency of use of each of the films and discovered that the three most frequently used films were three that our group would not at all recommend:

1. Alcohol, Crisis for the Unborn; 146 times in 5 years
2. Born Drunk; 168 times in 5 years
3. FAS, Films Inc.; 198 times in 5 years

We recommend that these films be removed from the Resource Centre and not be made available for borrowing. It may be necessary to purchase additional copies of the other recommended resources to fill the gap left by the removal of these videos.

1. **FAS IN NORTHWESTERN CANADA**. Length: 45 min.
   Produced by Health and Welfare Canada, 1979.

Content: Talking head of Dr. Asante lecture which utilizes actual case studies reviewed through interviews with mothers of FAS children and footage of the children. The lecture describes FAS and illustrates the characteristics and behaviour of affected children.

Strengths: Good footage of FAS children demonstrating characteristics and behaviour. Discussions with mothers have the impact of "testimonials".

Weaknesses: Difficult to understand and hard to follow in some places.
Slow moving and boring in sections.
Some misinformation regarding "safe amount" of alcohol.
Lacks clarity with regard to mental retardation.
Gives the impression that with early and appropriate care, there is a good outcome. There is no emphasis on the "lifelong" problems of affected children.

Audience: Health professionals and Paraprofessionals.

Rating: Poor. Not recommended because of need for updating and clarification.

2. **PREGNANCY ON THE ROCKS**. Length:30 min.
Produced by Peter Glaws Productions, 1981.
Hazelden Educational Materials,
Center City, MN, USA
55012
(602) 257-4010

Content: Provides a comprehensive overview of FAS: characteristics, epidemiology, and etiology based on recent research data. Families with FAS children are interviewed.

Strengths: Good overview. One of the better films reviewed in terms of the breadth and depth of information and the mode of presentation.
Interviews with families and footage of children provides insight into the seriousness of the problem and the difficulties of living with the condition. The interviews also serve as "testimonials".

Weaknesses: Does not deal with FAE or the fact that there is a "spectrum of effects".
The focus is on chronic heavy drinkers or alcoholics, thus giving the impression that FAS/FAE can only occur in those situations.
Tendency toward a "blaming approach".

Audience: General public, community workers, daycare workers, high school students.

Rating: Good. The development of a guide to accompany the film, which clears up the misinformation and updates the material would help to retain the value of this film.

3. **SOMETHING TO CELEBRATE**. Length:23 min
Seneca Productions Inc. for NNADAP, 1984.
National Native Alcohol and Drug Abuse Program
Health and Welfare Canada
Jeanne Mance Building
Tunney's Pasture, Ottawa, Ontario
K1A 1B5

Content: Amateur docu-drama dealing with the prevention of FAS. The film documents the experiences of a Native couple as they become aware of the dangers of drinking while pregnant. The woman decides to abstain despite social pressures encouraging her to drink.

Strengths: Generally good presentation of the factual information. Utilizes Native actors which make it appropriate for use with Native populations.

Weaknesses: Slow moving so it may not appeal to people with low motivation.

Audience: General Native population. Rural high school students.

Rating: Good.

4. **FAS. THE PREVENTABLE BIRTH DEFECTS**. Length: 20 min.
Produced by the Addictions Research Foundation and Association of Iroquois and Allied Indians. 1985.

Addiction Research Foundation
33 Russel Street
Toronto, Ontario
M5S 2S1

Content: The video presents the life story of Mary Atkins, now a grandmother, and her personal experience as a mother of children with Fetal Alcohol Syndrome. The presentation documents Mary's personal triumph over alcohol abuse and her current efforts to counsel others in order to prevent the devastating effects of FAS. Mary's story is interspersed with narrated segments presenting scientific information on the epidemiology, etiology and characteristics of FAS/FAE.

Strengths: A moving personal testimonial by a woman who has experienced the devastating effects of FAS first hand.
Material is, for the most part, up to date and accurate.

Weaknesses: Uses footage of a child who clearly has FAS while talking about FAE.
A more appropriate narrator would be a Native health care professional, or Native actor.

Audience: General Native population, Native high school students, community and daycare workers in Native communities.

Rating: Very good. Readily recommend for use in Native communities.

5. **PROGRAM 1: WHAT IS FAS?** Length: 24 min.
Lena Productions for B.C. FAS Resource Group.

Content: Describes the etiology, epidemiology and characteristics of FAS/FAE, prevention, diagnosis and treatment. Dr. Sterling Clarren is the main commentator. The presentation uses case studies and short discussions of various aspects of FAS/FAE by a number of specialists in the field.

Strengths: Use of range of experts in the field lends strong credibility.
Most of the information is accurate, up-to-date with only a few minor inconsistencies.
The case studies provide "testimonials" by parents of children with FAS.
Covers a vast amount of important information.

Weaknesses: Voice of narrator lends a cold laboratory feel to the film but content neutralizes this. A few inconsistencies and some vagueness; i.e. Dr. Clarren's comment on the amount of alcohol to produce effects; a mother's comment re: damage occuring only in first two months; a comment at the beginning of the film that FAS children are born to "alcoholic" mothers.
A lot of material is covered. Might lose people who are not well motivated.

Audience: Appropriate for health professionals and paraprofessionals, the educated general public, high school students, and pre-natal classes (portions of the film).

Rating: Good to very good.

6. **PROGRAM II: PREVENTION**. Length: 21 min.
Lena Productions for B.C. FAS Resource Group. 1989.

Content: The emphasis of this film is on prevention of FAS/FAE. There is some overlap of information with Program I. The introduction covers the etiology, epidemiology and characteristics of FAS/FAE. Presents interviews with families with an FAS child, and individuals who have FAS/FAE. Also uses range of experts in the field.

Strengths: Emphasis on prevention. Begins with the recognition that FAS is a community problem: the community creates the context in which drinking occurs and must deal with the problem.
Material presented is comprehensive and up-to-date. Emphasizes the need for early identification and intervention, and the need for community based strategies for prevention. Some useful ideas.

Weaknesses: Some inaccuracies, i.e. a mother stating that "the first three months are the most critical". This statement is a bit misleading without an explanation.

Audience: Appropriate for health professionals and paraprofessionals, the educated general public (could be presented in a workshop setting by knowledgable leader), high school and prenatal classes. Very good for community resource workers.

Rating: Good to very good. We recommend that an accompanying handbook for presenters be developed to accompany film.

7. **BORN DRUNK**. Length: 20 min.
Produced by American Broadcasting Corporation, 1979.
ABC Films, 1300 Avenue of the Americas,
New York, N.Y., USA, 10019

Content: Presents an overview of FAS. The film is sensational, fast-paced and hard hitting. Interviews with parents of FAS children are presented.

Strengths: None

Weaknesses: Sensational, and full of inaccuracies and misinformation. Outdated. Overtly racist with victim blaming approach. Steroptypes Native people. In interviews with foster parents of FAS children, the parents are white, while the FAS children are Native.
Does not address the long-term nature of the problem.

Audience: Would not recommend this film for anyone.

Rating: Poor. Recommend that the film be removed from the Medical Services Branch Resource Centre.

8. **PREGNANCY: OUR CHOICE, THEIR FUTURE**. Length: 20 min.
Produced by Canadian Learning Company,
Toronto Hospital for Sick Children, 1984.

Content: Presents an overview of the etiology, epidemiology and characteristics of FAS and the effects of smoking and drug use on the unborn baby. Focuses on a neonatal intensive care unit and two critically ill babies. Very graphic in parts. Interviews with parents whose infants suffer from the effects of alcohol and drug use by the mother/parents during prenancy are presented. A scene in a prenatal class with PHN answering questions about safe level of use in pregnancy.

Strengths: Interviews with parents have the impact of testimonials. The film takes the emphasis away from laying guilt and blame on the parents, while at the same time emphasizing personal responsibility. Does this very well.
Good general overview of FAS/FAE, with important prevention messages for parents.

Weaknesses: Graphic in parts. Some sections could be upsetting for pregnant parents who may not be prepared for the scenes. Editing and previewing is essential before presentation.

Audience: Health care professionals, paraprofessionals, community resource persons, and high school students with guidance. Portions of the film may be useful for use in prenatal classes.

Rating: Good.

9. **FAS: FILMS INC.** Length: 20 min.
Produced by Films Inc., USA, 1976.
733 Greenbay Road, Wilmette, Il.
USA, 60091

Content: Presents an overview of the etiology and characteristics of FAS through the use of case histories and interviews with parents of FAS children. Presents research, including animal/laboratory studies, by the original researcher who identified FAS in North America, Dr. David Smith.

Strengths: None

Weaknesses: Material is outdated.
Film is overtly rascist and perpetuates negative stereotypes of Native people. For example, the film compares a Native child with FAS to a healthy white child. Contains animal laboratory scenes that may be upsetting for some people.

Audience: Not recommended for anyone.

Rating: Poor. We recommend that it be removed from the Medical Services Branch Resource Centre.

10. **ALCOHOL: CRISIS FOR THE UNBORN**. Length: 30 min.
Produced by March of Dimes, 1980.
1275 Mamaroneck, Ave.
White Plains, NY, USA, 10605

Content: Presents an overview of FAS, including etiology and description of FAS characteristics. The film is narrated and presented by Dr. David Smith and Dr. Jones, the researchers who first identified FAS in the USA. Presents some good information on the identification of children with FAS. Reports on Chernoff Study. Other leading experts, e.g. Ann Streissguth, are included.

Strengths: Good overview of FAS, generally accurate and up-to-date information. Recommends abstinence during pregnancy, as a safe level of consumption has not been established.

Weaknesses: Promotes stereotype of FAS as a Native problem by comparing Native FAS child with healthy white child. A tendency to victim blaming, e.g. "crisis only a mother can create".

Audience: May be appropriate for health care professionals and paraprofessionals who can pick out relevant information and not get caught in the subtle imagery. Would not recommend for general public.
The same information is probably better presented elsewhere (e.g. Program 1 and 2, and others recommended above).

Rating: Fair.

11. **ONE FOR MY BABY**. Length: 20 min.
WHA Television, California. 1982.
AIMS Media, 626 Justin Avenue
Glendale, CA, USA. 91201

Content: Utilizes leading experts to describe FAS/FAE, diagnosis, etiology and epidemiology. The historical and social context of alcohol consumption and factors which contribute to FAS (e.g. advertising) are discussed. Two families with FAS children are presented.

Strengths: Discussion of the social and historical factors affecting alcohol consumption is generally good, but could be expanded.
Generally good overview of FAS, and some of the footage with parents is good.

Weaknesses: Tendency for a blaming approach.
Incidence data is a bit outdated.

Audience: General public, high school students, community resource people.

Rating: Good. There is a book that accompanies the film, "Just so it's healthy", which was not reviewed.

12. **20/20 Fetal Alcohol Syndrome**. Length: 40 min
Produced by ABC Television, 1990.

Content: Deals with living with FAS. Interviews several families including "Broken Cord" author and father of FAS child, Michael Dorris.

Strengths: Very well done. Commentary at the end of the film shows that the society still holds the view that "one drink couldn't possibly hurt".
The reality of the problems associated with FAS/FAE is well documented.

Weaknesses: A bit long for use in some settings.

Audience: Appropriate for general public, high school, pre-natal classes, community resource workers, Native communities.

Rating: Very good. One of the better films reviewed.

13. **FAS: VANCOUVER.** Local production of lecture by Dr. Smith. 1977. Length: 12 min.

Content: Local production of a medical inservice lecture by Dr. David Smith, original FAS researcher.

Strenghts: May be appropriate for target audience (i.e. medical practitioners).

Weaknesses: Boring. Does not handle the extent of damage in any detail.

Audience: Health professionals.

Rating: Poor. Not recommended.